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ABSTRACT

The book presents the results of a survey of the daily life and attitudes of 90 English families with an adolescent with Down Syndrome (DS). The first chapter reviews the typical development of DS children. Chapter 2 provides demographic data including schooling (94% attended schools for children with severe learning difficulties), residence (83% were living with their own natural families), and social class distribution (same as general population). Chapter 3 looks at daily living skills while the development of adequate communication skills is considered in Chapter 4, noting that 40% of the younger teenagers used only keyword utterances. Chapter 5, on achievements in school, reports that few of the teenagers had developed practical levels of reading, writing, or number skills. Chapter 6 indicates that most leisure interests tend to be passive and solitary. Chapter 7 looks at general behavior and concludes that most DS teenagers do not have serious behavior problems. The next two chapters, on physical and sexual development, finds the DS subjects to be shorter than average with sexual behavior rarely a problem. Chapter 10, on family life, reports that while the DS teenagers require a lot of attention and while their degree of independence is much less than that of their non-DS peers, their parents did not view these factors in a particularly negative light. The final chapter offers some typical case histories and conclusions. (DB)

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THE ADOLESCENT WITH DOWN'S SYNDROME

life for the teenager and for the family

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THE ADOLESCENT WITH DOWN'S SYNDROME

- life for the teenager and for the family

Sue Buckley Ben Sacks

Front cover photograph:

Roberta - aged 15 yrs - talking on the telephone
(Courtesy of Jon Marshall, Fareham Photographic Studio)

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INTRODUCTION

This book presents the findings of a survey of 90 families with a teenager with Down's Syndrome in the county of Hampshire, England.

The survey was conceived in the autumn of 1983 when one of the authors (Ben Sacks) was invited to talk to a group of parents at a branch of the Down's Childrens' Association on the topic of adolescent development.

While we both had quite a lot of knowledge of teenagers, their development and family life from our own personal and professional experience, we were forced at this time to recognise the fact that relevant published research was almost non-existent.

In the past twenty years, there has been a considerable interest in the early development of children with Down's syndrome and a large research literature has developed. However, teenage and adult life has been largely neglected - a point also emphasised by Professor David Lane and Dr Brian Stratford, the editors of the recent book "Current Approaches to Down's syndrome".

In designing our study, our aim was to try and find out what daily life was actually like for the teenager with Down's syndrome and for their families - in some depth. We wanted to know what range of skills the teenagers had acquired, how independent they were, what they had achieved at school and what kind of friendships and social lives they had out of school. We also wanted to know about their health, growth and sexual development and general behaviour at home. In addition, we wanted to gain some insight into the daily lives of their families in two ways, firstly in terms of the burdens of practical care which still existed and secondly a broader view of how the families felt that they had been affected by caring for their handicapped son or daughter. Finally, we asked families about how they saw the future, what they wanted for their son or daughter in adult life and what services they needed.

In designing our study, we were influenced and encouraged by the work of Elizabeth Anderson and Lynda Clarke, "Disability in Adolescence" (1982). This is a study of teenagers with cerebral palsy and spina bifida and it brings to life the impact of these handicapping conditions on the lives of the affected young people and their families.

In this study, the authors had interviewed both the teenagers and their families. While we are concerned about the way in which teenagers with Down's syndrome feel about themselves and their future, we felt that most of them would not be able to talk to us in a meaningful way about these areas of their lives, so we decided to limit ourselves to talking to parents at this stage. We will return to this point later in the book, with some suggestions for further research.

In 1983, when planning this research, we were not in receipt of a full-time research grant and did not plan an ambitious programme. Our initial intention was to contact all the families in our local health district (SE Hants), giving us a sample of 32 families, and to visit them with a questionnaire covering all the topics we wished to investigate.

The questionnaire was designed and piloted in the spring of 1984. Each family in the local area was contacted and visited with the help of a research student. Only one family was unwilling to take part.

Each family completed a detailed questionnaire and interview in their own home. All the information collected is based on parent's reports though each family was visited and in most cases, the young person was at home at the time of the visit. In one health district, the teachers of 25 of the young people completed the sections of the questionnaire covering their skills. The results correlated highly with the parents responses (Kalus 1986) confirming the views of the authors and others (Cunningham & Sloper, 1984, Gath & Gumley 1984) that parents are accurate observers of their childrens' behaviour.

The enthusiasm of the families for the project and the range of valuable information gathered from those local families led us to decide to try and extend the study to the rest of Hampshire. The larger the sample we could collect, the more reliable and useful the data - so we appealed to the Down's Childrens Association for financial support. Their help and local support enabled us to employ a part-time researcher and extend the study to the rest of the county.

As both of us have busy and demanding jobs, it has taken us longer than we had hoped to write this report. In preparing the information for publication, we have tried to write in a manner that makes the book reasonably easy to read and useful to parents and teachers, while still reporting the data accurately.

Many times, parents told us sadly that the early information they had been given by professionals about their child's likely progress had been either inadequate, inaccurate or unduly pessimistic. One reason for this may be the lack of suitable information available to professionals on the expected development of children with Down's syndrome. We hope this study will go some small way towards rectifying this situation.

The first part of each chapter contains a detailed presentation of the findings with tables of data and discussion of the statistical analyses we have used. The main findings are then summarised at the end of each chapter.

The only work similar to our own that we knew of in 1983 was that of Dr Janet Carr published in 1982. Dr Carr had been following the progress of a group of children born in 1963-64 and in 1982 she published the results of her visits to the families at 11 and 16½ years.

Since then information on teenagers has been published by Dr Ann Gath and Billie Shepperdson. These studies are discussed in some detail in Chapter 2 and their results presented throughout the book along with the findings of other relevant research.

On the whole, we have given most attention to research that is relatively recent, has been carried out in this country and looks at children born after 1960. The progress of children with handicaps depends on the type of early intervention and education available to them. The experience of families caring for a child depends to a large extent on the attitudes of their society to handicap and on the services and support they receive.

The children that we have studied were born between 1966-1973. They will all have received education from five years of age, but the majority had very little pre-school education or therapy. In reporting their achievements, we do not believe that they have all reached their maximum potential and would expect that if we repeated the study in ten years time, we would see the effects of pre-school intervention, increased integration and improved education reflected in increased achievements.

In presenting the results of the study, we have to present tables of statistics which, while important for the information they contain on the range of achievements and difficulties of these teenagers, do not convey the real personalities of the ninety young people that we are discussing.

We have included some case histories in the final chapter to try to bring the statistics to life.

The families and their young people were each, of course, unique yet the majority clearly shared one thing in common. Whatever their difficulties, these families loved their handicapped young person dearly. The teenagers were valued as people in their own right and were given a dignity and respect within their families so often denied them by the rest of society. The courage, determination and resilience with which most of the families have faced the task of bringing up their handicapped children never ceased to amaze us.

We were initially surprised by the enthusiasm most families showed towards participation in the study. It seemed they often felt that they had been sadly neglected and were delighted to talk to anyone really interested in their son or daughter. While we were asking for information about the present time, many families wanted to talk at length about their past experiences. Interviews frequently lasted several hours and we felt that many families had a largely unmet need for support and understanding. Sadly, most of these families had little or no help in the first years of their children's lives and experienced much loneliness, isolation and ignorance about their child's handicap. Too often, we heard sad tales of the very negative and unhelpful attitudes met from professionals in these early days. Hopefully, support for new parents is much more appropriate and positive now.

Many families offered to provide any further information if we wanted it and to take part in any future studies. We felt priviledged to share in the lives of each family and hope that our findings and conclusions truly reflect the experience of these families.

Chapters 2-9 present the main findings of our study of teenage development and life. We felt it important to include a chapter on Down's syndrome covering the main facts about the epidemiology and biology of the condition plus an overview of early development to set the scene rather than assume that our readers are familiar with this information already. Chapter 10 presents our conclusions and recommendations.

In order to make the text readable, we have avoided the constant repetition of the precise description "young people or teenagers with Down's syndrome" and in the main simply discuss them as young people or teenagers. We have also used "he" as a generic pronoun rather than try to constantly refer to "he or she" etc.

Sue Buckley
Ben Sacks
July 1987

CHAPTER I

DOWN'S SYNDROME - AN OVERVIEW

What is Down's Syndrome
Down's syndrome is the most common handicapping condition of childhood, affecting about one baby in every 660 live births.

It is a chromosomal abnormality. Chromosomes are tiny "X" shaped particles contained in every cell in the body. They are the structures upon which the genes, which determine our hereditary characteristics, are carried. An affected child has 47 chromosomes instead of the normal 46 in each of his cells. He has three of chromosome number 21 instead of two. (The normal 46 are arranged in 23 pairs - one of each pair comes from mother, one from father).

Over 95% of people with Down's syndrome have three separate 21-type chromosomes in every cell. This is known as non-disjunction type Down's syndrome. The abnormality in this case occurs when one of the sex cells (the sperm or the egg) divides unevenly during its formation so that instead of there being one chromosome 21 in each new sex cell, one has two and the other has none. Sex cells have only one of each chromosome, ie 23 in all. When the egg and sperm combine the usual set of 23 *pairs* is produced. When the cell with the extra chromosome 21 combines with a cell with one chromosome 21 the result is a cell with three - Trisomy 21.

The remaining 5% consist of two main types. One is called Translocation Down's syndrome. This is because a whole or part of chromosome 21 becomes attached to another chromosome and thereby adds the extra chromosome 21 substance to the cell. This type of Down's syndrome has extremely important consequences for subsequent births and the implications should always be discussed with a clinical geneticist.

The other type is called Mosaic Down's syndrome. A person with this type has two types of cells in his body - some have 3 of chromosome 21, the others the normal 2. There may be almost any ratio between these two types of cells. Mosaic Down's syndrome is very rare.

At the present time, no one knows what causes the cells to behave in these abnormal ways and to produce any of these types of Down's syndrome. A baby with Trisomy 21 can be born into any family. The condition seems to occur at about the same rate in all human populations studied.

One of the factors known to increase the risk of having a child with the condition is increasing maternal age. At the age of 20 the chance of having a baby with Down's syndrome is I in 2,000, at the age of 30 it is I in 1000, at 35 years I in 500, at 40 years I in 80 and at 45 years I in 18 (Hook and Lindsjo, 1978).

As soon as a baby is suspected of having the condition - usually very soon after birth - a small sample of his blood will be sent for analysis of the chromosomes. This analysis will confirm the diagnosis and the type of Down's syndrome. In some cases, usually the translocation type, blood will also be taken from his parents so that they can be advised on the risk of them having another affected baby. Many families go on to have further healthy babies but, regardless of the type of Down's syndrome affecting their own child, families should always seek the advice of a genetic counsellor before embarking on another pregnancy.

Diagnosis During Pregnancy

The affected baby can be identified during pregnancy by a test known as amniocentesis. Fluid is taken from around the baby at about 14 weeks into the pregnancy. Cells in the amniotic fluid come from the baby and, after suitable treatment, will show the extra chromsome if it is present. Blood can also be taken from the mother in the usual way and examined for alphafetoprotein (AFP), a substance which tends to be found in lower concentrations when the foetus has Down's syndrome. A calculation can be made which relates the level of AFP with the mother's age to give a risk factor for the likelihood of having a foetus with Down's syndrome. If this factor is sufficiently high, amniocentesis would then be offered for more certain confirmation. Chorion biopsy is a new technique which allows the diagnoses to be made earlier in pregnancy but is not readily available at present.

At the present time, amniocentesis is only offered to mothers of 35 years or older in most areas. It is only offered to younger mothers if there is some reason to suspect that they might be at risk of giving birth to a handicapped child. It will be offered - and if not, should be requested if wanted - to any mother who already has an affected child.

Of course, diagnosis is not the end of the story. If the developing baby is shown to be damaged, mother will be offered a termination. This is not an easy decision and must rest solely with the parents. Indeed, the authors know of several families with a young child with Down's syndrome who declined to have an amniocentesis when expecting their next baby as they felt unable to accept termination whatever the consequences.

The Physical Effects of Down's Syndrome

A baby born with Down's syndrome tends to have certain characteristic physical features; small differences in the shape of the head, the eyes, ears and bridge of the nose for example - which the experienced doctor or midwife may spot, though it is not always easy to do so. Several medical complications are more common in the babies, than in normal babies - but they do not affect all babies. Heart defects are common, affecting about 40% ofthe babies and sometimes require surgical repair. Another early problem may be intestinal blockage - also needing repair. Some babies are so poorly that they die in the first days or weeks of life. For example in one study of 40 children born in 1970-71 (Gath, 1985), 4 (10%) died in the first 2 months of life, a further 5 (12½%) in the first 2 years and a further 2 (5%) by nine years of age. This means that 11 or 27½% of babies died by 8-9 years of age.

In another study (Carr, 1975) 17% of a group traced at six weeks of age died before 4 years of age. One further child died before the 11 year follow-up and another before the 16 year visit, therefore 20% of this group died before reaching adulthood, the majority of these before 4 years of age. The most common physical problems which hamper the baby's early progress are hypotonia (floppy muscle tone) respiratory infections (colds, coughs and throat infections) ear infections, hearing and visual defects, and sometimes thyroid deficiency.

The reader wishing to know more about these medical problems will find detailed chapters on heart, hearing and vision in Lane and Stratford (1985) 'Current Approaches to Down's syndrome.' Good health care and exercise are important for the progress of the baby from the earliest months of life.

Early Development

The most important point to emphasise when considering the progress of any child with Down's syndrome is that the impact of the condition is variable. This is true of both the physical and mental effects. Some children are much more seriously handicapped than others and so the range of development is very wide.

Until recently, most studies of development assessed the children on standardised intelligence tests. These tests sample a range of the child's abilities, so that two children could achieve the same total score in different ways - with different strengths and weaknesses.

Despite the limited usefulness of intelligence test scores - as they tell us nothing about the child's actual repertoire of skills - they do give an indication of the range of ability of children with Down's syndrome compared with normal children.

Children who achieve IQ scores of 70 or above are considered to be in the normal range of intelligence. A score of 100 is average, a score of 120 or over is bright. Children who achieve scores of 50-70 are considered to have moderate learning difficulties. Children with scores below 50 have severe learning difficulties. They will be developing at a much slower rate than normally developing children.

In most published studies, children with Down's syndrome achieve scores varying from about 20 to 85 IQ points. This means that the most able children are achieving scores within the lower end of the normal range of development (about 70 and over) while the low scoring children must be seen to be very retarded in their progress.

It is often stated that the childrens' IQ's decline over the first few years of life - that is, a child will have a higher test score at 1 year than at 3 years. While this is often the case, it does not mean that the child's actual ability is declining; it just means that the baby is learning new skills at a much slower rate than the normal child and so falling progressively further behind in terms of test scores. It may largely reflect the changing nature of the test items at two, three and four years - when the normal child is making rapid advances in language development - the area in which the child with Down's syndrome is most delayed.

The following table indicates progress with some of the major milestones usually achieved in the first two to three years.

TABLE 1: NORMS FOR SOME EARLY MILESTONES FOR THE BABY WITH DOWN'S SYNDROME

	Mean age in Months	Range in Months
Smiles when touched or talked to	3	1½ - 5½
Turns to sound	7	4 - 11
Grasps a dangling ring	7	4 - 11
Sits steadily	11	8½ - 15½
Babbles da-da etc	11	7 - 18
Removes cloth to find toy	13½	10 - 21
Attempts to imitate scribble	15½	10 - 21
Builds tower of 2 cubes	22	15½ - 30
Says two words	22	15½ - 30
Walks 3 or more steps alone	24	15½ - 42

A more detailed account of early development, may be found in Cliff Cunninghams book "Down Syndrome: An Introduction for Parents". (Souvenir Press 1982)

Early Intervention

Most children now receive considerable help in the first few years of life. In most parts of the country, children receive physiotherapy, speech therapy and home teaching from a few months of age. Many of the children need and benefit from physiotherapy to improve their muscle tone and help them to sit, crawl stand and walk. The help of a speech therapist is invaluable from the first year of life. Communication begins between mother and baby from birth and these early foundations pave the way for speech to develop later.

The children are usually most delayed in the area of language development. Hearing loss of varying degree is common and may affect as many as four out of five babies (Cunningham & McArthur, 1981). In the past, defects in hearing and vision were often overlooked - they should always be checked for annually.

Some professionals encourage the teaching of signing as an aid to language development from the first years of life. Many feel that specific language teaching is essential and that speech therapy should begin early. The reader interested in more information on the research into language development in Down's syndrome will find a detailed account in Buckley et al 1986. They are very optimistic in their approach and feel that with teaching most children could achieve more than was usual in the past. We will return to language development again in Chapter 4.

Early education is available to many children from the first year of life, often provided by a teacher visiting at home on a weekly basis. The most common scheme in the UK is the Portage Early Education programme and a number of research studies have shown that children with Down's Syndrome make faster progress when receiving early education. (Buckley, 1984, 1985). The visits of the home teacher are also a valuable source of support for the family, especially for the mother. Early teaching is increasingly aimed at compensating for the children's specific learning difficulties though we still do not know enough about the precise nature of these.

The teaching methods learned in the Portage scheme give parents the skills which will enable them to continue to teach their children after the preschool years and to deal with any difficult behaviour they may encounter. Anyone wishing to know more about Portage and its benefits should read the most encouraging and informative book written by Jan Lloyd about her son's progress and entitled "Jacob's Ladder". (Lloyd, 1986)

At Five Years Old

To give the reader some idea of the expected progress of the child with Down's syndome, it is essential to emphasise again the wide range of progress seen in the children.

By five years of age, almost every child will be walking, running and climbing stairs quite competently. Most will be toilet-trained during the day - though they may still have occasional accidents and be less reliable at night. Most will be feeding themselves quite competently, though they may need their food cut up - and still be a little clumsy and a bit messy.

Most will be able to take off many items of clothes and put some on but will not be able to manage the fastenings and still need quite a lot of help.

Most children are happy, sociable and present no more behaviour problems than other children of their age, though they will not be as self-sufficient and will need more supervision.

Studies suggest that consistent training of skills and firm discipline improve the progress of the children and reduce behaviour problems. (Carr 1985, Shepperdson, 1984)

Progress in understanding and language is more difficult to summarise. Some children are talking quite well at five - in short sentences and may be beginning to read. Some are able to go to school in normal classes. Most children are talking in short phrases of one to three words and can make themselves understood at home and at school - but their language development is way behind that of the normal five year old.

A few children are not talking much at all by five years of age. They may be the ones with the worst hearing losses and may find learning to sign helpful. Similarly a few children will still be incontinent and very dependent - needing help with feeding, dressing and all daily activities. Often, the more severely mentally retarded children are those with the most severe physical damage to heart, eyes etc.

However, there is no reliable way to predict the progress of an individual baby with Down's syndrome. Several authors have looked for features that might be related to mental progress. Some suggest that birth weight and hypotonia are indicators ie babies with good birth weight and good muscle tone tend to be more advanced (Gath, 1984 Pueschel, 1984). However - these studies do not mean that these features can be used for prediction in any individual case. The authors know of individual examples where quite weak babies in the first year of life are doing very well intellectually at five years of age.

At present, in most areas, the majority of children are still placed in special schools at five. In the past, all children with Down's syndrome were placed in schools for those with severe learning difficulties - once called Junior Training centres, then ESN(S) schools and now schools for children with severe learning difficulties. Now - increasing numbers of our children go to schools for those with moderate learning difficulties, to remedial groups in ordinary schools, or into ordinary classes in ordinary schools.

This changing trend is clearly illustrated by the figures collected in South Wales by Billie Shepperdson. In her group of children born in 1964-66 in South Wales, in 1972, 25% of the group were not in ESN(S) schools but the choice became less as the children got older. In 1981, 77% were or had been in ESN(S) schools and 19% in ESM(M) schools - one child completed his education in a comprehensive school. However, when looking in 1981 at a group born in 1973-75 69% were not in ESN(S) schools at the age of 5¾ to 8¾ years compared to 25% for the same age group in 1972. (Shepperdson, 1984) In many areas, the education authorities are not as progressive as they seem to be in South Wales and a higher proportion of the children would still be in the current equivalent of the ESN(S) school - the school for children with Severe Learning Difficulties (SLD).

Developent at 8-9 Years

The expected range of development of children with Down's syndrome at this age can be obtained from looking at the results of a study of a representative group of 22 children of this age in Oxfordshire (Gath & Gumley, 1984) and another study in South Wales (Shepperdson 1984). In the Oxfordshire study the children were assessed using standardised intelligence tests and the Reynell Language Scales.

The intelligence test scores (IQ's) were very varied, ranging from below 20 to 79 giving a mean IQ for the group of 48. Two girls (9%) scored in the normal range with scores over 75, seven (32%) were mildly retarded with scores between 50 and 74; eleven (59%) were more severely retarded with scores below 50. There was a significant difference between the scores of girls and boys in this study, like most other studies. (eg Carr, 1982). The girls tended to be more able as a group, than the boys.

In the Gath study, teachers and parents completed the American Adaptive Behaviour Scale - which measures the child's range of everyday skills and achievements. For most children, their scores on the IQ test and the Adaptive Behaviour tests were quite closely related, though there were some exceptions. Some children were doing much better on the Adaptive Behaviour scale than would have been predicted from their IQ scores presumably because they had been specifically taught everyday skills. One of these children was being fostered by his teacher while his mother was training to be a nurse.

Two children did poorly on Adaptive Behaviour compared to their IQ scores, both had congenital heart disease and suffered symptoms which would hamper their physical activity.

The Adaptive Behaviour scores again covered a wide range. The children with the highest scores were very little different from normal children of the same age in self-help skills, social functioning and ability to communicate. At the other extreme, those with the lowest scores were very dependent, requiring help with all toilet functions, feeding and dressing, had poor communication and little play repertoire.

In addition to considering the general abilities of the children in her study at 8 to 9 years, Gath also looked at their language development and behaviour.

All the girls had some skills in verbal communication, but some of the boys were quite severely limited, four having a limited vocabulary or poor articulation. Five boys had no speech, one was beginning to sign and she found that the children with poor communication skills were more likely to have behaviour problems as a result of the frustration.

Over all, eight boys and three girls (half the total group) were felt to show some behaviour problems. Seven of these eight boys were those who had no language at all or only very limited language skills.

The whole issue of assessing the causes and significance of behaviour problems is discussed in Chapter 7.

Billie Shepperdson studied a group of 5½ to 8½ year olds in South Wales (Shepperdson 1984) and concludes that the children in her study showed much the same wide range of ability as those in Gath's study. She also points out that they follow the same pattern as normal children in that children from stimulating homes do better than those from the most disadvantaged homes. She found some disadvantaged families who had declined to take advantage of services such as Portage and that the lack of intervention and support had resulted in some extremely retarded children. This had created self-perpetuating situations in that, as the child might be increasingly difficult or unrewarding to take out and to play with, so even less was offered, resulting in even worse attainments.

This comment should not be misinterpreted. Some of the children are very damaged infants and however caring and stimulating their environment, it will not be able to compensate for

the biological damage. However, most Down's syndrome children are able to learn and their development will be affected by the quality of their environments both at home and at school. These environmental effects are demonstrated in our data throughout the book.

For any child, the range of skills and the behaviour he shows as he grows reflects *both* the biological make-up he inherited and the opportunities to develop that his environment has provided. It is a continuous and complex interaction.

The importance of the experiences and education the child receives are reflected in the studies of the IQ range of people with Down's syndrome over the past fifty years. Connolly (1978) reviews all the studies available at that time and shows that there has been a steady increase in overall IQ scores in each successive study. This must reflect changing attitudes, increased expectations, improved health care and improved education.

In conclusion, then, at eight to nine years - as at five years, there is a wide range of development with some children in the normal range and attending ordinary schools (2 in Gaths group of 22) and at the other end of the range a few very dependent children. Gath does not give much information which can readily give a picture of their range of everyday skills. However, Carr does, so we will finish this survey of childhood with her data on a group of 44 eleven year olds (Carr & Hewett 1982).

Development at 11 years

Carr has been following a group of children born in South London since birth. At 11 years of age all the children could walk, over half could feed themselves without any help and a further third needed help only with cutting difficult foods. All but 5 could wash and dry their hands and nearly half bath themselves. Three-quarters could dress themselves with minimal help and half could brush their teeth without help. Nearly two-thirds were clean and dry, day and night and another quarter had only occasional daytime accidents. Most of the children usually slept well but 14% were sometimes disturbed at night and one child had marked sleeping problems.

Over the previous seven years, half the children in the group had been in good health but 26% had been in poor health (only 5% of a comparison group of normal children had poor health in the same period). A third of the children in both the Down's syndrome and ordinary groups had suffered a serious illness - but more normal children had suffered a serious accident - 33% compared with 9% of the children with Down's syndrome. Nearly half of each group had been admitted to hospital at least once. About two-thirds of each group had gone on trips or holidays away from home.

Over half the children in each group were said to be calm, placid children, more of the ordinary children were said to be highly strung - one third compared to 9% of the children with Down's syndrome. Two-fifths in each group were said to be co-operative and three-fifths easy children to manage. Less than 30% of the children with Down's syndrome needed constant watching or ever had temper tantrums; only 20% were occasionally aggressive and 12% overactive. A third would sometimes lie, cheat or steal and over half could be rebellious or cheeky but for most this did not happen often. 40% could never be left in the house alone and only 7 left as long as an hour. Seven could go to the local shops alone. Over half the children were no problem to take out in public and just under a third caused only minor problems while four children (one severely and three profoundly retarded boys) were very difficult to take out.

Carr again reports the wide range of IQ scores (7 to 57 points - mean -37.2) rather lower over all than Gath's 8 to 9 year olds) with girls scoring higher as a group than boys. The mean IQ

score for the girls was 41.5 and for the boys 33.2. As a group the girls language ability was better than the boys, especially for expressive language. For the whole group language age scores lagged behind IQ scores, suggesting a specific language delay which cannot be entirely explained by cognitive delay.

In her study, Carr compares the progress, of the children growing up in their own homes with those children in care. At 11, 38 are in their own homes, six in care. While there is no significant difference in the intelligence test scores for the two groups, there is on the measure of language development. Children brought up at home have much better language development - especially expressive language.

Family Life and Care

About one in ten of the babies born with Down's syndrome are not taken home from the hospital after their birth. (This figure varies from place to place - possibly related to the support available to families).

However, once the baby is home, most families continue to care for their child at home.

In Janet Carr's study (Carr, 1975) for example, of 54 children born in 1963-64, nine (17%) were boarded out from birth. At four years of age, a further six were in foster-care. At 11 years of age, three more boys had gone into care - all were profoundly handicapped and there was illness in the families.

In Ann Gath's study (Gath, 1978) of 40 babies born in 1970-71 in one area, 5 (11½% were not taken home. When she traced these families 8-9 years later, three more children were now receiving care though they returned home some of the time. In two cases, the parents were young and experiencing various family problems including unemployment, in the third case, the child had severe behaviour problems.

Little is known of the reasons which lead parents to feel quite unable to care for their baby as soon as they know the diagnosis. It must be an extremely difficult decision to make and to live with as the years go by and maybe such parents deserve more understanding and support than they often receive. In some cases, where support is given and the family encouraged to keep in touch with the baby, they often become reunited after a few months. This has happened in several families known to the authors - though not reflected in either of the studies mentioned.

Increasingly, adoptive homes are found now for babies whose families feel unable to cope. This was rare before 1975 but will alter the future statistics on care placements.

Summary

A baby with Down's syndrome has an extra chromosome in every cell in his body and this abnormality produces all the symptoms associated with the condition. Although this extra chromosome was identified in 1957, we still do not know what causes this fault to occur.

The condition can be detected in early pregnancy by amniocentesis. Medical complications including heart defects, intestinal obstructions vision and hearing defects are more common than in normal babies and some quarter of the babies do not survive to teenage years.

The early development of the babies is enhanced by good health care, exercise, speech therapy and early education. There is a wide range of achievement among the children, with some clearly more damaged by the condition than others.

At present, most of the children will be identified as needing special educational provision and this will usually be provided in a special school though some are able to go to normal school at five.

By five, most will be happy, sociable individuals with no more behaviour problems than other children. They will be on the way to achieving independence in dressing, toileting and feeding themselves. The area of biggest delay is likely to be language, with most children talking, but in short sentences and with rather limited grammar.

Throughout childhood, the picture is much the same. All the children continue to make progress, but with a wide range of ability. Some children will be within the lower end of the normal range of ability, most will be moderately delayed and a few rather severely handicapped and dependent. The studies reviewed suggest that behaviour problems are no more common than in normal children and where they exist tend to be associated with limited communication. Accidents are less likely to happen to the child with Down's syndrome but health problems are more common. The children need more supervision, especially outside the home, than others of their age.

About 90% of the babies are taken home after their birth and cared for by their parents and the majority stay at home throughout their childhood. Fortunately, adoptive homes can often be found now for those babies whose parents feel unable to care for them as research shows that babies growing up in a family progress rather better than those in care, especially in the area of language development.

CHAPTER 2

THE TEENAGERS AND THEIR FAMILIES

In this chapter, we begin our report by describing some facts about the group of teenagers that we have studied and their families.

This kind of factual information is important as it tells you about the size and characteristics of the sample; it enables you to evaluate the significance of the findings reported in later chapters and it enables you to make comparisons between the findings of other studies and our survey.

Throughout the book, we review findings from other studies where relevant. There are three researchers whose work will be referred to quite frequently, Ann Gath, Janet Carr and Billie Shepperdson. For that reason, the relevant facts about their studies are included in this chapter.

Janet Carr, Ann Gath and Billie Shepherdson have carried out longitudinal studies, that is, they have studied the same group of children over a period of time. The Oxford group (Gath, 1978, 1985, Gath & Gumley 1984, 1986) have been followed from birth to nine years of age, the South London group (Carr 1975, 1985, Carr & Hewett 1982) from birth to 21 years of age and both studies included a control group of normal children for comparison. The South Wales group (Shepperdson 1984, 1985) were not followed from birth but were visited once in their early school years (5½ to 8½ year olds) and again in their midteens (14-18 years).

Our Hampshire study, and a second study by Ann Gath (Gath and Gumley 1986) are cross-sectional studies. That is, they are large samples of children containing groups of children at different ages, but only visited at one point in their lives. The benefit of longitudinal studies is that they may reveal causal factors contributing to differences between children, in a way that cross-sectional studies are unable to do, because the longitudinal study follows the same children over a number of years.

The South London Study (Carr, 1975, 1985, Carr & Hewett, 1982)
Janet Carr's sample comprised 54 children born in one Health District in 1963-64. There were 29 girls and 25 boys. The children were visited seven times between six weeks and 4 years of age and their early development is discussed in Carr 1975. She compared their progress with that of a group of normal babies born at the same time.

They were studied again at 4 years, 11 years, 16½ years and 21 years. The emphasis in this study was on the children and their development. It compares the progress of the children brought up in their own families with those in care from birth. It also provides some information on how families have coped with their situation over the years.

The South Wales Studies (Shepperdson 1984, 1985)
Billie Shepperdson studied a group of 53 children born in 1964-1966. There were 27 girls and 29 boys. They were visited in 1972 and again in 1981 (though only 37 of the 53 children took part in 1972). In 1981, the children were aged 14 to 18 years, so provide a useful comparison to our older Hampshire sample.

In 1981, for comparison with the 1972 study when the first group of children were 5-8 years old, Billie traced another group of 26 children, 14 girls and 12 boys born in 1973-75.

The South Wales study looked at the attainments of the children and how families cope both emotionally and practically. There is more emphasis on studying the families, their perceptions of their problems and the help they have received from services, than in the South London study.

The Oxford Studies (Gath 1978, 1985, 1986, Gath & Gumley, 1984, 1986)
Ann Gath's longitudinal study traces the progress of a group of 30 children born in Oxford in 1970-71. She has reported in detail on their development over the first two years of life and then again at 8 to 9 years of age, when 22, 8 girls and 14 boys, were still living. (Gath 1978, 1985)

In addition, she has carried out a cross-sectional study with a further large group of 192 children, 94 boys and 99 girls ranging in age from 6 to 17 years at the time of the study. (Gath and Gumley 1986)

The main aim of these studies was to focus on the emotional impact of the children upon their families. Families were assessed on the quality of marital relationships, parent's physical and mental health and the health and general adjustment of siblings. The children's development and general behaviour were also assessed.

The Hampshire Study (Buckley and Sacks, 1987)
The group that we have studied consists of 90 children aged 11-17 years, born between 1967 and 1974 and all resident in the county of Hampshire.

When we were planning the study, neither the South Wales nor Oxford studies of teenagers had been published.

Our aim was to try and find out what daily life was really like for the teenagers and their families. We knew that each teenager with Down's syndrome and each family would be unique in many ways. In order to be sure that the group one studies truly reflects this wide variety it is important to have a large and representative sample so that it includes children of all degrees of handicap and families of all sizes and backgrounds.

So we set out to trace every child with Down's syndrome in the age group of 11 to 17 years living in the county of Hampshire, England.

There is no precise definition of adolescence but a number of authors suggest that eleven years marks the beginning of this stage of development, with its rapid physical changes (eg Weiner 1970). Although the child with Down's syndrome is likely to be retarded in mental development, there is no evidence that the physical changes associated with the onset of puberty are delayed (see Chapter 9).

The upper limit of 17 years was chosen in order to facilitate the identification of the young people, as most would still be receiving full time education up to their 17th birthday.

The young people were traced with the help of the Education Department. We wrote to every special school in the county where children with Down's syndrome were likely to be placed and to each office of the School Psychological Service to trace those at school elsewhere in or outside the County. We also traced those who had left school for other placements. A total of 108 teenagers were identified and their families or carers were contacted by letter. The letter explained the purpose of the study and invited them to participate. A reminder was sent to those who did not reply.

90 (83%) families agreed to be interviewed and to complete a long questionnaire for us. This response rate of 83% is very similar to that reported by Cheseldine and Jeffree for a similar study in Manchester. They carried out a survey of thirteen to nineteen year old severely mentally handicapped young people and 87% of the families contacted agreed to participate. In their group of 214 young people, 37% had Down's syndrome.

Of those families not willing to take part in our study, illness in the family or the young person prevented them in 6 cases. Two were in schools for the mildly slow learners and perhaps did not wish to be identified with those with Down's syndrome as a whole. Discussions with the schools suggested that in 3 cases, the families probably felt unable to complete the questionnaires. There were no more than two non-responding families at any one school and information gained from the schools did not suggest that the development of the teenagers about whom no information was obtained was in any way significantly different from those who agreed to take part in the study.

The age and sex distribution of the 90 young people in the group we finally studied is shown in Table 2.1.

TABLE 2.1 THE TEENAGERS:- the age and sex distribution of the group

Sex	Under 14 N (%)	Over 14 N (%)	Total N (%)
Girls	18 (20)	22 (24)	40 (44)
Boys	28 (32)	22 (24)	50 (56)
Total	46 (52)	44 (48)	90 (100)

(N = number of teenagers in each group)

It is interesting to note that the sample divides almost exactly on age, half under 14 and half over 14, although there is a sex difference. We found 50 boys and 40 girls, and the 10 extra boys are all in the younger age group.

Others authors' have reported that more boys are found with the condition than girls (Lewis 1987) and that this ratio of boys to girls may be increased by a greater mortality for girls in babyhood (Scully, 1973, Carr, 1985).

The mean ages of the four groups are shown in Table 2.2.

TABLE 2.2 : MEAN AGE OF EACH GROUP

Sex	Under 14	Over 14
Girls	12yrs 3mths	16yrs 1mth.
Boys	12yrs 6mths	15yrs 6mths

Schooling
The majority of the teenagers were attending (or had recently left) special schools for children with severe learning difficulties (94%). Five (6%) were attending schools for those with moderate learning difficulties. Given the current trend towards integration and much greater expectations for the achievement of children with Down's syndrome it will be interesting to see if school placements change in the next ten years or so. As has been mentioned in Chapter I, this trend can already be seen reflected in changing patterns of school placements in South Wales. (Shepperdson 1984).

Home Circumstances
The majority of the children 74(83%) were living in their own home with their natural family. Eleven children (12%) were in full-time care placements, 2(2%) children were adopted and 3(3%) living in permanent foster homes. These figures are remarkably consistent with those found by other researchers. In the larger Oxford study 85% were living at home with their natural parents as teenagers (Gath & Gumley, 1986) and in the South London Study at 11 years of age, 78% were at home.(Carr & Hewett, 1982)

In the Oxford study 10% of the teenagers were in full-time care, 2% adopted and 4% in permanent foster homes.

The Families
We asked about the marital status of the parents and this is set out in Table 2.3. It can be seen that quite a significant number (19%) are coping as single parents. [In the South Wales teenage study, 25% were coping as single parents.]

For the sample as a whole 8% are divorced and not remarried. This compares with a figure of 5% divorced for all families in Hampshire, according to 1981 census data. It is difficult to know how to interpret these figures. It is quite possible that a parent with a handicapped child is less likely to remarry after divorce than a parent with only normal children. Once remarried, people no longer describe themselves as divorced in the census data. [Again, figures from the South Wales study are similar, 70% of the natural parents are still alive and together (72% in our group), 13% are widowed (9% in our group and 5% in the Oxford group) and 17% are divorced (including remarried) (compared to 15% total for all divorces in our Hampshire group and 5% in Oxford. This figure may be artificially lower than ours if it excludes those now remarried.]

TABLE 2.3: MARITAL STATUS OF CHILD'S NATURAL PARENTS

	Number	(%)
Married	65	(72)
Widowed	8	(9)
Single	2	(2)
Divorced (now single)	7	(8)
Divorced (now remarried)	6	(7)
Not known	2	(2)

Living in Care
Of the ten Hampshire children in care, 4 had parents now divorced, I had a widowed parent, I a single parent, 2 had parents still married and for 2 the family background was not known by the care staff completing the questionnaire as they had been in care all their lives. This means that 26% of all the children from single parent families are now in care, compared to only 3% of children from 2 parent families. Our data clearly suggests that when the burden of care falls on one parent alone it may well be too great for that single parent to carry. This may be because the practical demands are impossible to cope with if that parent has to work. Who meets the child from the school bus, for example? Who helps out when the child is ill?

Age of parents at child's birth
The age of the mothers' at the time their affected child was born ranged from 15 to 49 years, the mean age being 32.0 years. This mean is consistent with that of other studies. In the Oxford teenage study the mean maternal age was 33.5 years and in the South Wales Study 33.2 years.

Table 2.4 shows the age distribution of both mothers and fathers at the birth of the child with Down's syndrome. This information was available for 78 of the natural mothers and 67 of the natural fathers and is more informative than mean age.

TABLE 2.4: AGE OF PARENTS AT BIRTH OF DOWN'S CHILD (% in each age group)

	Age of Parents							
	15-19	20-24	25-29	30-34	35-39	40-44	45-49	Over 50
Mothers	6	19	17	14	19	21	4	
Fathers	1	13	19	18	19	15	12	3

This distribution emphasises the fact that any individual child with Down's syndrome is as likely to have a mother under 25 as a mother over 40. (25% of the mothers are over 40, 25% under 25). Similarly, the ages of the mothers of the 50% remaining are remarkably evenly distributed.

While the risk of having an affected baby increases with the age of the mother (see Chapter I), the actual incidence of births is fairly evenly spread across mothers of all ages, because the majority of women have babies when they are in their twenties.

In our study 25% of the mothers were over 40 at the time of the birth, in the Oxford study the comparable figure is 28% and in the South Wales teenage group born in 1964-66 28%. [However, for the younger group of children studied in South Wales, born in 1973-75, only 12% of mothers were over 40 at the time of the birth, presumably reflecting the effects of both amniocentesis and better contraception.]

Size of families and the position of the child with Down's Syndrome

The families in our study varied in size from one to seven children, with the mean being 2.8 children (the comparable figures are 3.44 for the Oxford study and 3.4 for the older South Wales group, 2.7 for the younger group).

Table 2.5 shows the distribution of size of natural families in the sample based on the 82 families for whom this information was available.

TABLE 2.5 NUMBER OF CHILDREN IN FAMILY

(Percentage of families of this size in the Down's Syndrome and normal sample

Hampshire samples	N	No of children in family			
		1	2	3	4 or more
Down's Syndrome	82	10%	33%	37%	20%
Normal	1046	8%	40%	27%	25%

Put in another way, 20% of the affected children had 3 or more brothers and sisters, 37% had 2, 33% had only one and 10% none. Since the evidence given later in the book suggests that our children rely heavily on their own families for companionship, brothers and sisters may be even more important in their lives than they are for ordinary children.

The position of the Down's child in the families is shown in Table 2.6

TABLE 2.6: POSITION OF THE CHILD WITH DOWN'S SYNDROME IN THE FAMILY

Study	N	Only Child	Youngest	Eldest	Middle
Hampshire	82	10%	54%	24%	11%
Oxford	192	11%	50%	22%	17%
S Wales(64-66)	53	7%	63%	13%	18%
(73-75)	26	8%	46%	42%	4%
Hampshire normal children	1046	8%	45%	26%	21%

In our Hampshire group 10% of the children are only children. Just over half the group are the youngest in the family.

A quarter of the group are the eldest in their family. Strangely, with one exception, all the rest of the group are middle children in families of three children. The only exception was a boy who was the third child in a family of five and one of twins. His twin was a normal sister. Again, the data from the other studies of children with Down's syndrome is very similar to our own.

In Table 2.6 we have included data on family position from a sample of normal Hampshire children born in 1965-7 (Fluck, M: personal communication). As you can see, the proportion of the children who are the only children or youngest is very similar for both groups. There are more children with Down's syndrome who are the youngest in the family (54% compared to 45% in the normal sample) and fewer children with Down's syndrome in the middle, (10% less). This suggests that some 10% of families who might have had more children in the normal course of events, limit their family after the birth of the child with a handicap so that the child with Down's syndrome then becomes the youngest rather than a middle child.

In Table 2.5 we have also included the data on the normal sample and you can see that there are fewer 2-child and 4 plus child families but more 3-child families in the Down's syndrome sample. This suggests that when the affected child is the first-born, most families who would have gone on to have another child still do so. If the affected child is second-born it seems that the family may be more likely to have another child than in a family who now have two normal children. They know they can have a normal child if the first is normal and the second affected, so have a third to complete their family and then stop. If the affected child is the third-born, then the family are less likely to have a fourth child. The last two suggestions would explain the inflation in the number of three child families in the Down's Syndrome sample.

If we consider the age of the mothers at the time of the birth, where the child was a first born, (ie only or eldest) you can see from Table 2.7 that mothers who are younger at the time of this first birth are more likely to have another child. (Group 2 in the Table). The mean age of the mothers where the Down's baby is the eldest is 23.68 years, while the mean age of the mothers where the child is an only child is 33.28 - a ten year difference.

TABLE 2.7: MEAN MATERNAL AGE AT THE TIME OF BIRTH IN RELATION TO THE FAMILY POSITION OF THE CHILD

Family Position	N	Mean Maternal Age
Only (first born)	8	33.28
Eldest (first born)	20	23.68
Middle	10	30.00
Youngest	40	36.02

(for statistical analysis see Appendix p 0.001 sig difference)

Social class of families

Each family has been given a social class rating based on the Registrar-General's Classification of occupations, using father's occupation. This information was available for 83(92%) of the families.

TABLE 2.8: SOCIAL CLASS OF FAMILIES
(based on Registrar-Generals classification of Occupations)

	Social Class	Families in Study	Population of Hants (1981 census)
I	Professional occupations	6%	8%
II	Intermediate	24%	28%
III	Skilled non-manual	13%	13%
III	Skilled manual	34%	32%
IV	Partly skilled	18%	14%
V	Unskilled	5%	5%

This sample of families shows no significant difference from the population of Hampshire as a whole.

In the past, several authors have suggested that there is a tendency for more affected babies to be born in the top two social classes, relative to the rest. This might be because mothers in these professional groups are more likely to be highly educated and have careers of their own and so delay childbirth (Gath, 1978, Shepperdson, 1985, Carr, 1975)

However, our data do not support this view, nor does the data on the teenage sample in South Wales. In order to assess the significance of the social class distribution of parents, they must be compared with the census figures for social class distribution in the areas in which they live. The sample must also be large enough to be truly representative. Our group of 90 and the South Wales group of 57 are the only two fulfilling both these criteria and neither show social class bias.

We went further and looked at the age of the mothers at the time of the birth for each social class grouping. As you can see in Table 2.9 there are no differences in the mean ages or the range, so no support for the view that the professional mothers are giving birth to the affected baby at a later age.

TABLE 2.9: AGE OF MOTHERS AT BIRTH IN RELATION TO SOCIAL CLASS

Social Class	Mean Age of Mother at Birth	Range	Standard Deviation
I & II	32.29	15.00 - 43.00	6.97
IIIn & IIIm	31.37	17.00 - 47.00	9.49
IV & V	31.65	18.00 - 44.00	8.89

(Analysis of variance p = 0.092 not sig)

It seems that the babies are born at about the same rate in all families regardless of any characteristic which might be reflected by social class, such as poverty and poor housing. This is not the case for many other handicapping conditions.

Summary

Ninety teenagers and their families took part in the survey. The teenagers were aged between 11 and 17 at the time of the interview, 40 girls and 50 boys. 18 girls and 28 boys were under 14 years of age and 22 girls and 22 boys were 14 years or over.

94% of the teenagers attended schools for children with severe learning difficulties, the remainder attending schools for those with moderate learning difficulties.

83% of the young people were still living in their own natural family. 2 were adopted, 3 in permanent foster homes and 12% in care. They were much more likely to go into care from a single parent than two parent family. The divorce rate among these families was not significantly higher than for all families in Hampshire.

The age of the mothers at the time of the birth ranged from 15 to 49 years, with the actual incidence of births quite evenly spread across the age range. 25% of the mothers were under 25 at the time of birth, 56% under 35.

A child with Down's syndrome is more likely than a normal child to be the youngest in the family and less likely to be a middle child. He is also more likely to be in a 3 child family and less likely to be in a 2 child or more than a 3 child family. Where the baby with Down's syndrome was the first born, mothers who were young at the time were more likely to have another baby than those who were older.

The babies were born at the same rate in all social class groups, contrary to the predictions of some previous writers. The ages of the mothers at the time of birth shows the same distribution in each social class group.

CHAPTER 3

ACHIEVING INDEPENDENCE IN EVERYDAY LIVING

The aim of this research project was to find out what everyday life was really like for a teenager with Down's syndrome and for their family.

The first area of the teenager's skills that we asked about were the everyday living skills of dressing, washing and haircare, managing alone in the toilet, competence at the table and learning to prepare meals, lay the table and wash-up.

Not only is success in all these areas important for the competence and self confidence of the young person, it will also significantly reduce the daily burden of care in the family.

All children are a full-time job when they are little, needing help in all areas of self-care but by the time they reach adolescence, they are likely to be fully independent of their parent.

The main change in the teenage years is the move away from needing the practical help, support and supervision of parents towards increasing self-sufficiency and independence. Many teenagers not only become self- sufficient but also begin to take their share of family chores, washing up, preparing meals, mowing the lawn and cleaning the car. Some 69% of ordinary teenagers share two or more chores in the family each week according to one study (Anderson & Clarke 1982). The practical burdens of everyday care no longer exist and parents, in particular mothers, usually welcome this change - even if it is replaced with anxieties of a different kind which come with the teenagers demands for freedom and independence. Parents welcome the increase in time that they now have for themselves.

We suspected that for many of the families with a teenager with Down's syndrome, these changes at adolescence will not be so apparent and that the burdens of everyday practical care may still be considerable in some families.

Dressing

A summary of the teenagers achievements at dressing independently is given in Table 3.I. We have divided the total sample of 90 young people into four groups for the purpose of analysing the information. This enables us to see if there are any significant differences between the progress of boys and girls and also to show the improvement with age.

Answers are classified so as to reflect as closely as possible what parents told us, as skills are obviously not acquired in an all or none fashion. *Yes* means the teenager has achieved full independence in that area. *Mostly* referred to those who are almost independent but just need a little help. *With help* refers to those skills needing a significant amount of help every time they have to perform the activity. *No* means still completely dependent on an adult in this area. *Sometimes* covers all those times when parents said their son or daughter *could* do something independently - but only did so sometimes!

The conventions used in this table are used throughout the subsequent Tables. While presenting the data for all four groups may make the tables look complicated once you become familiar with the format you may easily compare boys with girls and see the improvements with age. It also allows the Tables to be used for norms, ie guides to what may be expected of a boy or girl at a particular age.

All figures are percentages and show the achievements for each of the four groups. If you look at question I in the table, 72% of the girls under I4 can dress themselves without any help and 73% of those over I4. For the boys, 57% of the under I4's and 77% of the over I4's have reached this degree of independence, suggesting the boys are a little slower in achieving independence in this area in the younger age group but catch up with the girls as they get older.

TABLE 3.1: EVERYDAY LIVING SKILLS - DRESSING

	SEX	YES		MOSTLY		SOME TIMES		WITH HELP		NOT AT ALL	
		-14	+14	-14	+14	-14	+14	-14	+14	-14	+14
1. Can dress without any help	G	72	73	17	22			6		5	5
	B	57	77	35	18			8			5
2. Does dress without help each day	G	39	45	44	28	11	9			6	18
	B	46	72	25	5	4	9			25	14
3. Can undress without help	G	78	77	16	18			6	-	-	5
	B	75	91	17	-			8	5		4
4. Manages all fastenings	G	22	55	61	14					17	31
	B	29	28	32	45					39	27
5. Chooses and finds own clothes each day	G	66	75			11	5	6		17	20
	B	57	68			4				39	32
6. Takes off and hangs up coat	G	17	36	6	5	72	45			5	4
	B	29	46	4	13	64	32	3			9
7. Finds and puts on coat	G	56	54	-	5			34	32	5	9
	B	50	68					46	27	4	5
8. Can choose appropriate clothes for weather	G	56	59			6	5		4	38	32
	B	50	63	4						46	37
9. Chooses own new clothes	G	84	68				5		4	16	23
	B	64	51			11	9			25	40
10. Shows preference for fashion styles	G	77	59							23	41
	B	29	45				5			71	50

NB Figures shown are in percentages for each of the four subsamples

Key to notation used in all Tables.

B = Boys -14 = Under fourteen
G = Girls +14 = Over fourteen

As you can see most of the teenagers can dress and undress with very little assistance but they need encouraging to use this ability in the everyday situations.

For each group except the older boys, quite a few who can dress unaided do not in fact do so every day.

In question 2, (Does dress each day without help), the main reason given by parents for dressing children who could in fact dress by themselves was the pressure of time; it was quicker on school days in particular to help the child. 7 of the younger girls and 8 of the younger boys had to be helped to speed them up. For the older children, 5 of the girls but only 2 boys still needed this type of help.

Other reasons given for children not dressing themselves when they could included feeling unwell, being in a bad mood, and being distracted by other activities. Five children would not dress on schooldays but all did so with no prompting at weekends and in the holidays!

When managing the fastenings on clothes, it was laces and buckles that most children were still struggling with, having mastered zips and buttons and overall the girls seem to be doing rather better than the boys.

The rest of the questions in the table move from just looking at dressing as a practical skill to choice and real independence during the day. The answers to question 5 (chooses and finds own clothes each day) show that around two thirds of the young people were choosing what they wore each day and finding these clothes from their drawers and cupboards themselves.

They were all much better at finding their coats than remembering to put them back in the right place when they came in (questions 6 and 7). This seems much like normal teenagers!

Over half could choose clothes which were appropriate for the weather (question 8).

When it comes to choosing new clothes the majority of our teenagers were already aware of what they liked, aware of current fashions and were encouraged to choose their clothes by their parents (questions 9 and 10), particularly the girls.

Throughout this section, you can see that the teenagers' skills are increasing with age and that there is a tendency for the girls to be a little more advanced than the boys.

The other studies of teenagers with Down's syndrome have not published as much detailed information on the young peoples' skills as our own. In the Oxford study, everyday living skills are not reported. In the South London study, at 16 years of age, Carr reports that over 50% of the teenagers could dress without any help and a further 25% mostly (compared to 75% and 20% respectively for our older children). All but 3 of the South London group of 43 could undress without help, making them very similar to our group. (Carr & Hewett, 1982)

In the South Wales teenage group, only 25% are said to be able to dress completely independently and 38% could choose their own clothes in the morning. (Shepperdson, 1984) However, it is difficult to make comparisons between these studies as we are not certain how other authors define independence.

In a study of 214 severely mentally handicapped teenagers in Manchester (Cheseldine & Jeffree, 1982) the author's report that 33% of the adolescents could dress and undress totally independently (compared to some 70% of our teenagers) and that 77% could select appropriate clothes for the weather (compared to some 60% of our group).
It should be noted that, while the majority of our group of teenagers are doing well and will achieve complete independence in dressing, there are a small number of young people who are very dependent and may remain so.

There are six teenagers who are unable to dress or undress themselves and show no progress in any of the other areas of dressing we asked about.

In a study which included a group of ordinary teenagers (Anderson & Clarke, 1982) 75% were choosing their own new clothes, so our teenagers compare well with all teenagers in this respect.

Personal Care

TABLE 3.2: EVERY-DAY LIVING SKILLS
PERSONAL CARE

QUESTION		YES		MOSTLY		SOME TIMES		WITH HELP		NO	
		-14	+14	-14	+14	-14	+14	-14	+14	-14	+14
1. Can wash unaided	G	43	78	12	-			34	13	11	9
	B	50	40	4	18			21	37	25	5
2. Can dry self unaided	G	61	78		5			33	8	6	9
	B	50	59		9			42	28	8	4
3. Can clean teeth unaided	G	77	82		5			12	4	11	9
	B	71	77		9			21	5	8	9
4. Can brush own hair	G	88	82						5	12	13
	B	82	82		5				4	18	9
5. Does brush own hair	G	22	37			17	9		9	61	45
	B	25	37	8						67	63
6. Can wash own hair	G	6	23					33	36	61	41
	B	11	23			7	4	29	23	53	50
7. Can wash in bath	G	89	86					6		5	14
	B	86	82	-	5				4	14	9
8. Can run bath water	G	55	46					12	18	33	36
	B	32	55					4	5	64	40
9. Can cut finger and toe nails	G	6	14					5		89	86
	B		9					3	5	97	86

Table 3.2 shows the teenagers range of achievements in personal care skills. When it comes to washing and drying themselves (questions I and 2) the older girls are clearly doing well but the boys are lagging behind. Only one in five of the older girls needed any help with washing compared with half of the boys. For both younger groups around half still need help with washing, though this was mainly to see that necks and ears were not neglected! Three quarters of all the groups could clean their teeth (question 3) and when help was needed it was usually with managing the toothpaste.

Areas where more help was needed and probably more specific teaching were in learning to wash hair, cutting nails and running the bath water independently (questions 6,8 and 9)

Four out of five teenagers could brush their own hair but would not do so unless prompted (questions 4 and 5). Most ordinary teenagers become concerned about their appearance in early teens, boys and girls alike. Maybe these handicapped youngsters need to be encouraged to be proud of their appearance and to check themselves regularly in the mirror.

It is important to encourage our youngsters to feel proud of themselves and to develop a positive sense of identity and self-esteem. This clearly begins in small ways, by encouraging them to take a pride in their appearance and clothes.

Our results show that in these areas of personal care, as with dressing, the majority of the teenagers are doing well and will achieve independence with a little more teaching and encouragement. However, we still see the small group of more severely handicapped teenagers represented, the nine or ten who still need almost everything done for them and are not even able to wash by themselves in the bath.

Turning to the results of the other studies, Carr & Hewett report that three-quarters of their sixteen year olds could do at least most of their own washing, bathing, drying and teeth cleaning. (Carr & Hewett, 1982) This figure is very similar to our own.

In the South Wales study, the only comparable figure reported is for bathing. Only 28% of the teenagers did not need any help with bathing, except assistance with rinsing the bath. (Shepperdson, 1984)

In the Manchester study of all severely mentally handicapped teenagers including those with Down's syndrome, the questions on cleanliness put slightly more emphasis on the teenagers ability to be totally responsible for themselves. In their group, 32% would wash themselves when appropriate, without being told and 21% took a bath or shower regularly without supervision. 35% were reported as brushing their teeth adequately and regularly, while 13% cared for their hair, including washing it, unsupervised. 52% were able to blow and wipe their nose when necessary and a further 22% could wipe their nose when told. (Cheseldine & Jeffree, 1982).

Toileting

TABLE 3.3: EVERY-DAY LIVING SKILLS
TOILETING

QUESTION		YES		MOSTLY		SOME TIMES		WITH HELP		NO	
		-14	+14	-14	+14	-14	+14	-14	+14	-14	+14
1. Fully continent at night	G	94	91							6	9
	B	79	100	11						10	
2. Fully continent by day	G	94	82		9		9			6	
	B	75	86	14	14					11	
3. Goes to toilet by self	G	94	95							6	5
	B	92	95							8	5
4. Manages clothing unaided	G	94	91						5	6	4
	B	67	77	7	5	4		22	14		4
5. Wipes self unaided	G	50	77		5			34	14	16	4
	B	50	54	4			5	32	32	14	9
6. Pulls chain	G	72	78			16	13			12	9
	B	71	73	4	5	7	9	8	4	10	9
7. Washes own hands	G	28	31	6		5	9			61	60
	B	18	50	4		14	5			64	45

As you can see from Table 3.3 (questions 1-3) almost every teenager is fully continent and well on the way to coping quite independently with the toilet. Though there are three teenagers who are still doubly incontinent day and night and two more still regularly incontinent at night. The boys 40 needed more help with clothes after using the toilet (question 4) than the girls. While the majority are taking themselves to the toilet without any prompting, five young people are not and still have to be taken and toileted by parents.

When it comes to wiping themselves clean in the toilet (question 5) the older girls are in the lead again. Half of the other three groups still need some supervision. In terms of everyday care, helping with toileting must still be quite a regular chore for more than half of the parents of these teenagers.

Most of the children were rather lazy when it came to remembering to wash (question 7). 50% or more in every group did not wash their hands unless told to do so and in this respect the older boys were doing better than the girls.

The incontinent were the more profoundly handicapped teenagers. Those few who still had occasional accidents did so for a variety of reasons. Three occasionally wet themselves if they laughed too much. Five wet at night if worried, six if ill, one when over excited, one when coping with change. Illness or worry accounted for occasional soiling at night by three children and one girl soiled occasionally during her periods.

The one area which parents and teachers needed to work at was independence in cleaning themselves after using the toilet. We suspect parents find it hard to tolerate a phase where the teenager is not too successful and so soils pants. This phase may be necessary in order to help them achieve independence.

When we look at the data from the other studies of teenagers with Down's syndrome they are very similar to our own.

Carr & Hewett (1982) report that 88% of their group were clean and dry both night and day and only three young people had occasional accidents. Shepperdson (1984) reports that in her group of 53 teenagers, 5 were still doubly incontinent, 23% still wet the bed occasionally (compared to less than 10% of our group) and just over half (55%) could cope with going to the lavatory by themselves. She also reports that two teenagers were prone to having soiling accidents while swimming and we had one similar case reported.

Shepperdson points out that parents of the few severely dependent teenagers coped with the considerable practical burdens of incontinence without complaint. For one or two older girls, in her sample and in ours, this could mean sometimes dealing with beds soiled by double incontinence and menstruation.

More worrying perhaps, is the danger that parents accept incontinence problems when, in fact, the teenagers could be trained. Secondly in our experience as in Shepperdson's, there were cases where medical treatment had transformed the lives of incontinent boys - but only after many unnecessary years of incontinence.

Parents and professionals must always be wary of falling into the trap of assuming that problems are an inevitable part of a handicap and cannot be changed. Sometimes they are - but that opinion should only be accepted once all possible treatment and training has been tried.

In Cheseldine & Jeffrees group of all severely mentally handicapped teenagers, 58% could use a familiar toilet appropriately when necessary, flushing the toilet and washing their hands, with no help needed. Some 75% of our older teenagers could do most of these things, but lagged behind a bit on washing hands unless prompted.

Mealtimes

The next aspect of everyday living skills we asked about was mealtimes. Table 3.4 summarises the answers to questions about table behaviour.

TABLE 3.4: EVERY-DAY LIVING SKILLS
MEALTIMES

QUESTION		YES		WITH SOME HELP		NO	
		-14	+14	-14	+14	-14	+14
1 Eats same food as the family	G	94	100			6	
	B	96	100			4	
2 Chews properly	G	77	91			23	9
	B	89	77			11	23
3 Eats independently	G	61	73	22	14	17	13
	B	53	77	25	5	22	18
4 Holds mug in one hand	G	94	95			6	10
	B	89	77			11	18
5 Can use all cutlery	G	88	100			12	
	B	96	91			4	9
6 Does eat with knife and fork	G	88	95			12	5
	B	96	91			4	9
7 Eats tidily	G	100	95				5
	B	93	95		5	7	
8 Takes food from serving dishes	G	78	91	6		16	9
	B	71	77		5	29	18
9 Help self to salt, pepper, sauces etc.	G	66	78	12	9	22	13
	B	64	86	4		32	14
10 Can eat in restaurant	G	100	91				9
	B	100	91				9

As you can see, the teenagers are all really competent at the table and need only a little help in cutting up some foods.

TABLE 3.5: EVERY-DAY LIVING SKILLS
PREPARING A SNACK

QUESTION		YES		WITH SOME HELP		NO	
		-14	+14	-14	+14	-14	+14
1 Can help self to biscuit	G	100	95				5
	B	85	86	8	5	7	9
2 Can help self to water	G	89	100	6		5	
	B	89	86	4		7	14
3 Can help self to squash	G	83	91	6	5	11	4
	B	50	82	32	9	18	9
4 Can help self to glass of milk	G	89	95	6	5	5	
	B	75	86	14	5	11	9
5 Can make sandwich	G	61	73	27	18	12	9
	B	39	50	32	31	29	19
6 Can made a piece of toast	G	50	55	33	31	17	14
	B	35	46	15	40	50	14
7 Can make a cup of tea or coffee	G	23	59	44	27	33	14
	B	18	45	21	28	61	27

The only four teenagers whose parents felt unable to take them to a restaurant (question 10) were the more profoundly handicapped. Almost every young person was described as able to eat tidily (question 7). This obviously is important in making them welcome when out visiting at friends or eating in public.

Table 3.5 looks at the teenagers ability to begin to prepare simple snacks for themselves.

The answers to questions 1-4, show that most can help themselves to a biscuit and a cold drink, though fewer of the younger boys than girls could make squash or fetch their own milk. In both age groups fewer boys can make a sandwich, toast or coffee. Around half of the older teenagers are able to make toast and a hot drink independently and about another third of the older ones could do so with some help.

Table 3.6 samples a few of the skills needed to begin to learn to cook.

TABLE 3.6 - EVERYDAY LIVING SKILLS - LEARNING TO COOK

QUESTION		YES		WITH SOME HELP		NO	
		-14	+14	-14	+14	-14	+14
1 Can open a can	G	17	28	22	31	61	41
	B	8	23	14	22	78	55
2 Can heat beans	G	12	23	22	41	66	36
	B	11	9	17	36	72	55
3 Can boil an egg	G		14	23	50	77	36
	B	4	5	17	22	79	73
4 Can fry an egg	G		5	23	40	77	55
	B		5	15	13	85	82
5 Can fry sausage or bacon	G			23	46	77	54
	B			18		82	100
6 Can use the oven	G		5	23	31	77	64
	B		5	15	13	85	82
7 Can use the grill	G		14	45	40	55	46
	B	8	19	17	18	75	63

As you can see, the majority of the teenagers have made no progress at all in these areas. Around three quarters or more of the younger ones and half the older ones have none of these skills yet.

Most parents had not, in fact begun to teach their teenagers to cook, so that these figures do not necessarily reflect failure and we suspect that these skills could have been developed to a much greater extent at this age. Parents were often anxious about the risks involved in learning to use kettles and cookers. They did not know how much their youngsters were learning in these areas at school and no one was involved in a teaching programme with the support of school.

To finish on a more positive note, you can see from Table 3.7 that the majority of the young people were good at laying and clearing the table at mealtimes and well on the way to mastering the washing-up.

TABLE 3.7 - EVERYDAY LIVING SKILLS - WASHING-UP AND LAYING THE TABLE

QUESTION		YES -14	YES +14	WITH SOME HELP -14	WITH SOME HELP +14	NO -14	NO +14
1 Can wash-up crockery	G	67	60	27	31	6	9
	B	35	50	36	36	29	14
2 Can wash-up saucepans	G	38	45	45	36	17	19
	B	22	31	39	28	39	41
3 Can dry crockery	G	67	78	6	13	27	9
	B	39	63	43	19	18	18
4 Lay the table	G	72	78	28	9		13
	B	68	82	21	13	11	5
5 Clear the table	G	78	77	16	18	6	5
	B	64	86	28	9	8	5

The other studies of teenagers with Down's syndrome do not report much detail in these areas of development. Carr & Hewett (1982) do not mention mealtimes or cooking at all. Shepperdson (1984) reports that 83% of her 14- 17 years olds could feed themselves entirely unaided and only 6% needed help at every meal.

Cheseldine and Jeffree (1982) report that their group of all severely mentally handicapped young people were doing well at mealtimes. 69% of the adolescents were able to feed themselves competently, with no assistance required and 80% could drink in a normal fashion without spilling. 56% of the group were said to have good table manners with 71% able to help themselves to food at the table.

When it came to eating out, only 32% could help themselves to a meal on a tray at a self-service cafe unsupervised, although 74% could tell or show their parents what they wanted. 85% were reported as being no trouble at all (eating without fuss) in unfamiliar places.

When it came to preparing food, 77% could make a cold drink from squash etc and 51% could make a hot drink. However, only 3% were able to prepare a complete meal unsupervised. 51% of the group could set a table correctly for a small number of people and clear the table after a meal. 31% of the group could wash, dry and put away dishes when necessary without supervision.

Our Hampshire teenagers are rather better than the Manchester group in all these areas. Some 75% of our older group are eating independently, and some 90% drinking in normal fashion. Over 80% can make a drink of squash and lay the table. Over 60% can wash and dry crockery. However, figures in the "no" column in each table remind us that there are the group of more dependent young people, six of whom still need to be partially fed at the table, ten who cannot hold and drink from a cup with one hand and four who cannot be taken to eat in a restaurant.

The Manchester group includes teenagers with Down's syndrome. They are 37% of the sample. Since our group are more advanced in most of these skills, it suggests that those with Down's syndrome may be more able in these areas than most severely mentally handicapped teenagers. Alternatively, our sample includes all teenagers with Down's syndrome, a number of whom (6%) were more able and would not be classified as ESN(S) as they were in ESN(M) schools. Such able teenagers would not have been in the Manchester sample.

The wide range of achievement
Having considered in detail the teenagers achievements across this range of everyday living skills, you can see that some youngsters are more independent than others in some or all areas.

We went on to analyse our data to see if we could find any reasons for this range of achievements. The most obvious reason for the range of achievements may be biological ie, that some young people are more severely damaged therefore more delayed in their progress than others. Indeed some of the young people do seem to have more severe learning difficulties suggesting that the extra chromosome does more damage to some than to others. In addition, some young people have far more severe health problems than others and illness may delay progress.

Apart from biological factors the progress of the child with Down's syndrome is likely to be influenced by a range of family and social differences in the same way as any other child. Perhaps children with brothers and sisters close in age are helped by having them to copy and encourage them. Alternatively, only children may benefit from more time and attention from their parents. The resources that some families and schools offer the children are better than others. We had collected information which enabled us to look at the possible influence of these and other factors on the progress of the young people and so we went on to analyse this.

In order to analyse the information statistically, we gave teenagers scores for each of the skills achieved in a carefully graded manner, giving more credit for a fully independent skill than a partially mastered one. In this way, each young person achieved a score in each area of everyday skills, dressing, toileting, personal care, meal time skills, preparing snacks, washing up and table laying. Their scores in each area were than added together to give an overall score for their achievement in everyday living skills. We could now begin to analyse the data to see what factors may be affecting their progress in achieving independence in these skills.

Sex Differences
Table 3.8 shows the mean overall scores achieved by the boys and the girls for the whole sample of ninety teenagers. The maximum score possible was 124.

TABLE 3.8 - EVERYDAY LIVING SKILLS - SCORES ACHIEVED

	Number	Mean Score	Stnd Deviation	Range
Boys	50	90.12	24.29	17-123
Girls	40	94.55	23.99	22-124

The mean score for the girls is 94.55 and for the boys 90.12. While these means show that the girls are slightly ahead of the boys in all the everyday living skills, this difference is not large enough to be statistically significant. A difference of this size could have occurred by chance.

For readers wishing to study the statistical analyses in detail, they are included in an Appendix at the back of the book.

In addition to analysing the total scores on everyday living skills achieved by the boys and girls, we also analysed their scores in each separate area of achievement. There were no significant differences between them in any of the skill areas we measured (dressing, toileting, personal

care, mealtime behaviour, preparing snacks, washing up etc.) except on the scores for preparing snacks. In this area, the boys lagged significantly behind the girls, probably reflecting the tendency to teach girls to cook, rather than boys!

Our data here does not support the view of some authors that the boys are significantly more delayed than the girls in all areas of their development. This issue will be discussed more fully in Chapter II.

Improvement with Age

Table 3.9 shows the mean overall scores achieved for the younger and older teenagers. The mean score for the younger teenagers is 88.46, and for the older ones, 95.88

This improvement with age is large enough to be statistically significant ($p = 0.03$). This is very encouraging as it shows continued and significant progress is being made as the teenagers get older. When we look at each separate area of achievement, every skill shows improvement with age.

TABLE 3.9 - IMPROVEMENT WITH AGE
EVERYDAY LIVING SKILLS - TOTAL SCORES

	Number	Mean Score	Stnd Deviation	Range
Under 14	46	88.46	23.17	22-118
Over 14	44	95.88	24.79	17-124

Effects of Ill-health

Having considered the influence of the young person's gender and age on their achievements in these everyday living skills, we looked at various other factors that might be important.

Progress might be hampered by ill-health. Health problems are discussed in more detail in Chapter 8. For the purposes of statistical analysis, the young people were given a rating for health problems, explained more fully in that chapter.

Table 3.10 shows the influence of poor health on achievement in everyday skills; we can see there is a tendency for poor health to delay the young person's progress. The young people with no health problems or only minor ones are doing rather better than those with moderate or severe problems.

TABLE 3.10 - THE EFFECTS OF HEALTH PROBLEMS ON EVERYDAY LIVING SKILLS

Health Problem	Numbers	Mean Scores - ELS
No health problems	30	97.7
Minor health problems	26	96.7
Moderate health problems	20	81.4
Severe health problems	14	86.7
	90	92.1

(For statistical analaysis see Appendix p = 0.21 ns)

Family Position

Next we considered the influence of the child's position in the family. This analysis is shown in Table 3.11. (This information on the family was not available for 8 of the children in care).

The table shows that only and youngest children are doing rather better than eldest and middle children. While this trend does not reach statistical significance, it is a trend which also holds for many of the skills we have looked at in later chapters.

It suggests that the only children and youngest children are benefiting from their parents or older brother's and sister's being able to give them more time and attention than is possible in families with younger children.

TABLE 3.11 - THE EFFECT OF FAMILY POSITION ON EVERYDAY LIVING SKILLS

Family Position	Number	Mean Score ELS
Only child	8	99.00
Eldest child	21	90.52
Middle child	10	90.60
Youngest child	43	93.30
	82	

(For statistical analysis see appendix, p = 0.64 ns)

Social Class Effects

Each family was assigned to a socio-economic group according to the Registrar-Generals

Classification of occupational status as used in the National Census. The full figures are set out in Table 2.7 in Chapter 2. As the number of families in Groups I and V were so small we have regrouped the data into 3 instead of six groups for the purposes of statistical analysis.

Table 3.12 shows the mean scores achieved by the youngsters in each social class group for the 83 for whom we had this information.

TABLE 3.12 - EFFECT ON SOCIAL CLASS ON EVERYDAY LIVING (ELS) SCORE

Social Class	Number	Mean Score ELS
I & II	25	96.48
IIIn & IIIm	35	94.71
IV & V	23	81.13
	83	91.48

(For statistical analysis see appendix, p = 0.05 sig)

The scores show that the youngsters in the social class groups IV and V are the lowest achievers. This effect is statistically significant. These families are likely to have fewer material resources and the families were slightly larger. Parents will perhaps have less time to spend with their children and be more likely to be adversely affected by poorer housing and relative poverty. Such social class effects on development are found for all children.

Schools

TABLE 3.13 - MEAN EVERYDAY LIVING SKILLS FOR THE TEENAGERS IN THE MAIN 5 SCHOOLS

School	No of Children	ELS Mean Score	Range
1	11	91.9	26.0 - 115.00
2	11	97.55	68.0 - 114.00
3	13	100.46	61.0 - 118.00
4	13	98.38	51.0 - 117.00
5	13	71.23	17.00 - 116.0
1 - 5	61	91.90	17.00 - 118.00

The young people attended a number of schools throughout Hampshire. In some schools there were only one or two children and obviously children in schools for moderate learning difficulties were the more able children in the sample.

In five of the schools for children with severe learning difficulties there were sufficient numbers of children in each school for us to compare their progress across schools. The results are given in Table 3.13.

Statistical analysis shows the variation between schools to be statistically significant. There is no reason to suppose that the group of children in each school is not representative of the range of the condition at the outset. A further analysis showed that there was no significant social class bias in any one school to account for poorer achievement (see Table 5.14). Nor were there any differences between schools on illness scores to explain this difference. We must conclude that some schools are doing a better job than others and provide a more effective learning environment for their pupils.

Summary

The results of this survey show that most of the young people are making good progress towards achieving independence in every-day living skills.

The majority of the teenagers can dress and undress independently, needing only a little assistance with difficult fastenings. Some needed encouraging to always do these things by themselves everyday and parents need to be firm about setting standards of achievement and insisting on them being maintained every day.

When we look at personal care and hygiene, again almost everyone is on the way to complete independence. Most teenagers still needed to learn to fill the bath, wash their hair unaided and to cut finger and toe nails, but could manage most other personal care tasks by themselves. There was evidence here, as elsewhere, that skills mastered were not always actually used daily so once again parents need to be sure they insist on good standards - such as hair always being brushed before breakfast and before going out everyday.

All the teenagers were fully continent day and night except for the few with severe health problems. Some had occasional accidents when upset, but on the whole incontinence is no longer an issue by this age.

Self-care when using the toilet is also achieved by the majority. Parents are still assisting some youngsters to clean themselves and need to work harder at teaching them to be independent even if it means tolerating slightly soiled pants for a while until they become competent. Many were lazy about washing hands unless prompted - another area for setting and insisting on good habits.

Eating habits and table manners were good for almost everyone, to a level where all families were happy to eat in public with their son or daughter.

The skill which lagged behind was learning to cook and prepare simple meals for themselves. Here achievements were much more limited than we suspect they needed to be. Some parents were afraid of the dangers of kettles, grills and cookers but many simply had not begun to encourage or teach their youngsters to prepare their own snacks or drinks. No doubt some were learning at school but not practising the same skills at home. This is clearly an important area for school-home liaison.

In fact, of course, all aspects of learning for these young people will be much more effective if schools work closely with parents so that the same skills are being learned and practised at home and school at any one time.

Our analysis of the information we collected shows that the progress of the young people in these areas tends to be delayed if they have poor health.

The boys seem to lag behind in some areas though they were not significantly behind the girls overall. We suspect that there is a bias towards encouraging the girls earlier with some of these skills - particularly in taking a pride in their appearance and in learning to cook.

Certainly there is no evidence that the boys are less able to learn. Our "top-ten" achievers for the combined Everyday Living Skills Score are a group of four girls and six boys! There is a steady improvement in skills with age in all the areas we looked at.

Our data shows that for most of the young people, their progress is related to the social world they live in and the experience and opportunities it offers them, like all other children. Some schools were doing a better job than others. Some young people were benefiting from being only children or the youngest in the family, so having more help from parents and older brothers and sisters. The advantages of higher socio-economic status also affects their progress, presumably because poorer families have fewer material resources and time to give to their children.

We will return to the significance of these findings again in subsequent chapters and in our recommendations in the final chapter of the book.

However, while this overview describes the progress of the majority of the sample, there are a group of some 9 teenagers who are more severely handicapped and still very dependent upon their parents in all areas of self-care.

CHAPTER 4

ACQUIRING ADEQUATE COMMUNICATION SKILLS

The Development of Communication

Most of us take our communication skills for granted. We learn to talk with amazing ease as toddlers. We acquire an enormous vocabulary of words and we learn how to put these words into sentences to convey what we want to express by the age of four to five years. The ability of the human brain to develop language is quite phenomenal and still little understood. The normal infant can be seen to have strategies for learning the meanings of individual words and for learning the rules for combining words into sentences, but we know little of how he does this at such a rapid rate.

Speech is not the only form of communication. We understand facial expressions, gestures and tones of voice. Most of us find it hard to imagine what life would be like for us if speech had not come so easily. Most infants begin to talk early in the second year of life, but they have been communicating in other ways with their mothers since birth.

Early pre-verbal communication is social and emotional in nature. The baby can convey his emotional state, how he feels, by laughing, crying and grizzling. He uses a mixture of sounds and facial expressions to do this. He and his mother can engage in social communication where they simply enjoy each others company. Tickling games at nappy changing time, peek-a- boo, baby talk games are all examples of social communication where each partner is simply enjoying the pleasure they are giving the other.

Once speech develops, it is also used to convey emotional feelings and for enjoyable social exchange. However, the most powerful advantage of speech over non-verbal forms of communication, is its ability to code an infinite amount of information. The child with speech can exert control over his world and expand his understanding of that world and the people in it at a very rapid rate.

Language development is the area that gives the child with Down's syndrome the most problems. Many studies confirm that progress in early language is delayed for a variety of reasons. Currently a lot of research effort is focused on the language learning difficulties of our children and anyone wishing to read a current review is referred to Buckley et al, 1986. and Miller, 1987.

Any child who has severe language learning difficulties will be seriously impaired in many other areas of his development as he is at a great disadvantage in all his interactions with others.

Development in Adolescence

There are very few studies of the language skills of teenagers with Down's syndrome and none that look at the practical usefulness of their skills. Many studies concentrate on assessing the vocabulary, grammar and syntax of children's speech and compare it with normal language development.

Others look at the way mothers and children talk to each other but again focusing on the actual words used by each partner and comparing them to normal mother/child interactions. Very few studies actually look to see if the communication was successful, ie did the child make

himself understood. This is what communication is about - one person being able to convey a message to another and be understood.

Limited and immature grammar and syntax, or poor articulation, need not be a cause for great concern if the message is still adequately conveyed and understood. One study which includes teenagers and young adults (Evans, 1977) shows that they tend to speak in utterances which do not have a normal English sentence structure and they also have articulation and fluency problems.

Many young people with Down's syndrome seem to have difficulty mastering all the complex rules of grammar and sentence construction and so tend to speak in what we call "telegraphic" or "keyword" speech. The following examples from the parents records we collected illustrate this type of speech eg "Fink its for me", "not get up", "school me?" "me poorly", "me not naughty". Secondly the young people often have articulation and fluency problems, ie they do not pronounce words very clearly and may stammer or repeat themselves, especially when excited or anxious.

These two difficulties combined may make it very difficult to understand their speech.

Most standard assessments of language, while giving an approximate idea of the level of language skills a child has, do not give any indication of how the child uses these skills in every day life, nor how successful his attempts at communication are.

A Look at the Effectiveness of Communication

We only had a fairly brief section on communication in the questionnaire, but we designed the questions to try and gain a picture of the young person's ability to communicate effectively in everyday situations. Short sentences and limited grammar may not matter too much, so long as people actually understand what they are trying to say.

TABLE 4.1 - USUAL LENGTH OF UTTERANCE

	Number of Words											
	1		2		3		4		5		5+	
	-14	+14	-14	+14	-14	+14	-14	+14	-14	+14	-14	+14
G		4	12		6	5	12	5		9	70	77
B	11	5	7	5	15	5	8	10	3	5	46	70

(Figures = percentages)

(Based on 87 teenagers as 3 still have no speech, 1 younger girl and 2 older boys)

In addition to answering some specific questions about their youngsters' communication skills, parents were asked to record verbatim examples of the actual speech their teenager used in a variety of everyday situations and how they coped when they were not understood.

The data collected is at best only a sketchy overview but it does reveal some interesting and important issues. Three of the ninety teenagers had no speech at all, one girl and two boys.

For the 87 with speech, we asked parents about the length of utterances their children usually used. The results are shown in Table 4.l

While over 70% of all the girls and the older boys regularly use utterances of five words or more, only half of the younger boys do so.

Conversely, l8% of the younger girls and 33% of the younger boys are limited to communicating in three word utterances or less, and 10% of the older children are equally limited.

These utterances may be adequate for making themselves understood but show a lack of use of basic grammatical and syntactical structures.

Table 4.2 summarises the answers to several questions of significance for everyday language use.

TABLE 4.2 - EVERYDAY COMMUNICATION

		YES		MOSTLY		SOME TIMES		NO	
		-14	+14	-14	+14	-14	+14	-14	+14
1 Can say proper sentences	G	56	73		5	6		38	22
	B	60	40				14	40	46
2 Parents usually understand	G	88	86		5			12	9
	B	86	73		9	4	10	18	
3 Strangers usually understand	G	45	32		27	17	9	38	32
	B	10	18	8	28	15	5	67	49
4 Uses sign language	G	45	46					55	54
	B	67	28					33	72

Around 60% of the younger children of both sexes are said by their parents to use grammatical sentences rather than 'key-word' ones though we did not measure the grammatical complexity of these sentences and suspect that they would be immature.

73% of the older girls but only 40% of the older boys use grammatical sentences.

Around 40% of the younger children use only "keyword" utterances. The picture for the older children is not much better for the boys, but for the older girls 22% are still limited to key words. "Me go school?" instead of "Am I going to school?" or "Bike out?" instead of "Can I have my bike out?" are keyword phrases which have the main information carrying words in, but do not contain the words necessary to express the request in accepted English grammatical form.

Despite these difficulties you can see from question 2 that parents are good at understanding their own child. Though, 10% or so of the teenagers do have difficulty even making themselves understood at home.

The answers to question 3, 'Is your child's speech so clear that a stranger in a shop could understand him?' begin to give a true picture of the communication problems of these young folk as soon as they move out into the real world and try to talk to people in shops, on buses, or at clubs.

Less than half the girls and less than a fifth of the boys are able to talk to strangers and be understood. The problems are usually twofold - the limited grammar and the odd keyword utterances made worse by poor articulation.

Many parents told us that their son or daughters speech was less intelligible when excited and that they often had to ask them to slow down. Sometimes the young person is willing to try again and repeat what they are trying to say more slowly, sometimes they give up - as the following quotes illustrate.

"She is incomprehensible when she rushes. If I try to get her to repeat she says "Doesn't matter".

"She needs to be slowed down - she mixes up words when she rushes."

"He will often stutter, trying to find the right words. If you ask him how he does something like make a sandwich, he will say it in a very jumbled up fashion, with all the information given but not very clearly. He has had hardly any speech therapy."

"He is happiest in a routine, so he does not need to talk much. Every now and then, however, something will crop up that will capture his imagination and then he will go to great lengths to try and make us understand. Usually its very hard to get him to expand any statement he makes"

"Like all Down's children, she cannot always be understood. If I don't understand something and ask her to repeat it she says "Oh leave it Mum" - unless of course its something she really wants or needs."

"Some people find her difficult to understand as she cannot phrase sentences properly and does not speak with the confidence of normal people."

"She is easily overlooked when surrounded by other people in conversation, as she is not able to contribute as quickly to the current topic and often has to wait for a quiet moment to get a word in."

"He uses elaborate role-play to aid his speech when relating the days events, performing not only his own role but also those of the other participants".

The majority of these young people find it difficult to make themselves understood in the world outside school and home. It is hard for most of us to imagine what life is like if you cannot communicate.

These teenagers will find everyday tasks like shopping, travelling and buying food in a cafe really difficult without help. Even more worrying perhaps are the limits such poor communication places on everyday social contacts. Making friends, chatting to neighbours - all social contacts from superficial ones to important close relationships will be extremely difficult for these young people.

Finally a reminder that in this area of communication we have the same wide range of ability as we see in all the areas we have looked at, as these quotes from the parents of one very able and two very handicapped teenagers illustrate vividly,

"Everyone remarks on her excellent speech, if she can't think of a word or expression she wants to use, she will think for a minute and will use other words to describe it and will persevere with various expressions until you understand what she means."

"I can communicate with my son only by actions. I show him his dish for mealtimes, take him to the toilet at different times hoping he will use it at that time, if not we try again a little later. Really we manage quite well."

"She is reluctant to do anything which involves speech and if pressed resorts to tears or tantrums. She has difficulty controlling her tongue."

Signing

Many parents told us how often their teenagers resort to extensive use of natural gesture to try and make themselves understood, as they have learned that it helps as the following quotes illustrate.

"If I don't understand what he is telling me he tries to describe it with his hands."

"Mostly she can make other people understand with a mixture of signs of her own making and gestures with limited words. Strangers cannot understand her as well as close friends."

"She has always made herself understood either by pointing or gestures or just helping herself, despite her lack of hearing and speech. She has never received any speech therapy yet we feel this would have been a great help to her and still could be."

Many schools now teach sign language, usually Makaton.

Table 4.3 illustrates the use of signing by those who do use specific sign language.

TABLE 4.3 - USE OF SIGNING BY THOSE WHO CAN SIGN

		YES		SOME TIMES		NO		NOT KNOWN	
		-14	+14	-14	+14	-14	+14	-14	+14
1 Uses more than 10 signs	G	75	60				20	25	20
	B	48	67			61	16	21	17
2 Understands more than 10	G	75	60				20	25	20
	B	53	67			21	16	26	17
3 Parents find signs helpful	G	50	40	25		25	60		
	B	53	34	37	33	10	33		

The question referring to sign language asked about the use of a specific sign system like Makaton. Makaton has become widely used in special schools in the last six or seven years, so many of these teenagers are probably too old to have been taught to sign. Many people believe that signing should be taught as an aid to learning to talk in infancy and will help children with Down's syndrome to overcome some of their language learning difficulties. This issue is discussed in the book already cited (Buckley et al, 1986).

As many of our youngsters resort to gesture to help when they cannot make themselves understood, teaching them a sign system which can be used to represent spoken English might well be an advantage, as it is for other language delayed children. Such a system could also be an aid to teaching the grammar they find hard to learn. This is an important issue which needs further research.

The expression of feelings

Apart from the importance of language skills when getting to know people, another important function of language is as a means of expressing how you feel and sharing your worries.

We asked how these teenagers coped when ill, when upset or when frustrated. When ill 67% of the younger girls and boys and 77% of the older ones had a variety of simple phrases such as "not well" "me headache" "my tummy hurts" which were adequate or they could talk quite appropriately about their illness. Most of the rest just became very quiet and parents guessed that they were unwell, with only two boys and four girls resorting to crying to express feeling ill.

When it comes to being frustrated or upset, those young people without adequate speech resorted most frequently to tempers and tantrums or crying to express themselves though only half the girls ever showed any of these behaviours and half the younger boys and only a quarter of the older ones. Nine parents actually stated that their teenagers were never unhappy and certainly the descriptions given suggest that, with just very few exceptions the young people were a rather easy going lot and when they did get upset, very quickly got over it as only three were described as ever sulking.

Fantasy friends and fantasy play

In the course of meeting the teenagers and discussing their language skills, we observed two other unusual features of their language. These may be partly a function of immature development and partly the result of social isolation.

The first feature we noticed was a tendency to talk to themselves aloud in a self-regulating fashion, to instruct themselves through practical activities like dressing, and to tell themselves how to behave eg "don't swear, its naughty". As one parent put it "She will think out loud quite often". This may suggest a delay in the development of internalised, silent speech, ie inner speech for thought.

The second feature noticed was the tendency to have fantasy friends and to talk to toys and dolls. We noticed these unusual features during the first part of the study and from then on we began to ask each family we visited if the teenager had a fantasy friend or friends or if they still engaged in self-talk and fantasy play.

Of the 66 families asked, 32(49%) of the teenagers had fantasy friends or engaged in regular fantasy play or self-talk. One lad has a fantasy playmate called "boy" and can often be heard in conversation with him when in his room. He will tell "boy" things his mother has said to him.

One girl has a range of dolls that are treated as fantasy playmates. She will play with them for hours, using them to speak through when reading, feed them at the table and even place the blame on them if she is naughty. Another had an imaginary friend called "Gary" until he moved to his current school and often pointed him out to his mother on a bus or across the road. He was rather puzzled one day though when his sister came in and said "I've just seen Gary on the bus".

Often this play involved acting out worrying emotional experiences. This kind of play is typical of the normal four year old and seems to be a healthy mechanism for dealing with worries and anxieties. The following quotations illustrate what the parents told us.

"He has a number of teddy bears which are named after people. These have a terrible life because he will take out and act out his emotions with these bears".

"He has an imaginery playmate who is like a shadow - always with him. He will often talk to it and blame it if something is wrong". "She creates lots of imaginary games - like playing what has happened at school, talking to her school friends and teachers".

Most of us are able, by our teenage years, to talk about our fears and worries with either friends or parents - or at the very least we have the inner language to think them through in our heads. Handling emotional problems is going to be very difficult if you cannot talk about them and they may express themselves in other ways.

Parents gave examples of bedwetting as a reaction to worries - this may be the only way that some children could show their anxiety. One young girl lost all her hair when her parents parted and her father left home. Her mother realised this was a stress reaction but her paediatrician claimed the child was too dim to be worrying! Another young man in care also lost his hair when distressed by the loss of his keyworker.

The other function of the fantasy friends and play seemed to be social. The young people seemed to be creating the friends they do not actually have in real life.

"He will spend hours talking to and laughing with four of his cuddly stuffed animals. They are alive to him and he will relate the days events, reply to their questions and even laugh at their jokes. He has had these friends for years - the teddy bear is 13 years old."

"She has a collection of little Fischer Price men. She arranges them and talks to them frequently. They all have names and she never forgets any nor gets mixed up despite the number involved."

"He has his own playmate, a stuffed mouse who must be taken everywhere. He will talk through it and chatter away to it for hours."

"She has imaginary playmates with people of her own age, often someone she has actually met. More recently these have been boys." (a 16 year old).

We looked at all the other information we had on the teenagers to see if those engaging in fantasy friends and play differed from those who did not in any way that might help us to understand this phenomenon more fully.

However, we found that the two groups showed only one difference. Those inclined to a fantasy life showed significantly more difficult behaviours (see Chapter 7). The mean score for difficult behaviour for the fantasy group is 9.90, for the non-fantasy group it is 6.35. This difference is statistically significant.

Perhaps both the difficult behaviours and the tendency to create one's own social world are reflections of the social isolation from the normal world that many of these young people seem to experience. As Anderson & Clarke (1982) point out, "The concept of "social isolation" can be applied in many senses; to individuals who cannot properly communicate their feelings; to members of a group which is not integrated into the community as a whole (even if the members have a great deal of mutual contact); or to individuals who have few relationships and activities compared with others in society, in particular their peers. Handicapped people may experience isolation in all or any of these senses".

On all the other measures of the teenagers development that we have apart from difficult behaviour, there were no differences between the fantasy and no fantasy groups which might explain why half the teenagers do have fantasy friends or play and half do not. There were as many boys as girls in both groups and as many younger as older children. There were no differences in any of the achievement scores (Chapter 3 & 5) or the social scores (Chapter 6).

One interesting point, which may be important however, is that very few of the teenagers in care engaged in fantasy play. Of the eleven young people living in care, two were in the fantasy group, seven were not and in two cases the staff were not sure. On the basis of the data for the whole sample we would expect half to engage in fantasy play and this is clearly not the case for those in care. In a children's home, the young people have constant companions or are kept occupied by adults and are not lonely or bored suggesting that social isolation and boredom for those at home may be a factor. If this reasoning is correct, one might expect more of the only children to be in the fantasy group but this is not the case as you can see in Table 4.4.

TABLE 4.4 - TENDENCY TO ENGAGE IN FANTASY
IN RELATION TO FAMILY POSITION

Family Position	No Fantasy	Fantasy Play	Number
Only child	3	3	6
Eldest child	9	8	17
Middle child	1	5	6
Youngest	16	14	30
	29	30	59

(chi-square p = 0.42 ns)

Half of the only, eldest and youngest children engage in fantasy play, while five out of the six middle children do so.

The only children probably benefit from more adult time, so although they have no siblings, they do have plenty of real social interaction with their parents.

The parents of middle children in busy households may well find it difficult to spend time with them.

As these youngsters have communication difficulties, it may require the skill and patience of adults to really relate to them and understand their feelings, so that brothers and sisters may not always be able to compensate for limited parental attention.

There is no signficant difference between the fantasy and no fantasy groups on communication scores. The mean score for the fantasy group is 11.84 and for the no fantasy group is 12.26

This seemed to us to be a little surprising. One might have predicted that the poorer the teenagers communication skills, the more tendency to retreat into a fantasy world. However, it may be that almost all of our teenagers do not have adequate communication for the social world, so all are equally at risk for this psychological isolation.

Factors which may influence communication skills

Each young person's communication skill was given a numerical score which could range from 0 - 18 depending on their progress across all the measures we took. We were then able to look and see what factors might explain the range of differences the teenagers show.

First we looked to see if there were significant differences between the progress of the boys and the girls and you can see from Table 4.5 that for the sample as a whole the boys are signficantly behind the girls in their development of effective speech.

TABLE 4.5 - MEAN COMMUNICATION SCORES FOR THE BOYS AND GIRLS

	Mean Score	S D
Boys	10.80	5.19
Girls	13.65	5.17

(This difference is significant p = 0.01)

This finding has been reported in other studies (Gath & Gumley, 1984, Carr & Hewett, 1982) and it is illustrated in all the earlier Tables. For example in Table 4.2 only 10% of the younger and 18% of the older boys can be understood by strangers, compared to 45% of the younger and 32% of the older girls.

In Table 4.1 you can see that 18% of the younger and 9% of the older girls are still usually speaking in utterances of three words or less, while for the boys the figures are 33% and 15% respectively.

Both groups are improving with age and it may be that the boys are simply developing speech at a slower rate but will catch up in the end (though this will not apply to the very handicapped group).

We cannot offer any explanation for this increased delay for the boys, except to say that for all normal children it is also the case that on average, girls learn to talk earlier and show fewer speech and language problems than boys do.

TABLE 4.6 - MEAN COMMUNICATION SCORES FOR THE UNDER 14's AND OVER 14's

	Mean Score	S D
Under 14	11.33	5.40
Over 14	12.84	5.23

(This difference is not statistically significant)

Table 4.6 shows that for all the teenagers, their skills are continuing to improve with age.

The effect of family position

We went on to look at other factors which might influence the young person's progress with communication skills.

Table 4.7 shows the mean scores according to the young person's position in the family and Table 4.8 shows the mean score for the teenagers in different socio-economic groups.

The pattern of communication scores for teenagers according to their family position shows the same trends as all the other achievement scores, even though the differences do not reach statistical significance. You can see from Table 4.7 that the only children are doing the best and the middle children the least well. It would seem that adult attention and help is having the same positive effect on progress with speech as it did with every day living skills.

TABLE 4.7 - THE EFFECT OF FAMILY POSITION ON COMMUNICATION SCORES

Family Position	N	Mean Comm. Score	S D
Only	8	14.50	4.20
Eldest	21	12.14	5.10
Middle	10	9.80	4.10
Youngest	43	12.63	5.36
Total	82	12.34	5.10

(Kruskal Wallis ANOVA p = 0.32 ns)

The effect of social class

The pattern of communication scores for the teenagers according to the socio-economic status of their families shown in Table 4.8 suggest that those in the most disadvantaged homes do show slower progress. These families are likely to experience the effects of poorer housing, less money and probably have less time to spend with their handicapped youngsters.

TABLE 4.8 - THE EFFECT OF SOCIO-ECONOMIC STATUS ON COMMUNICATION SCORES

Socio-Economic Group	N	Mean Comm. Score	S D
I & II	25	11.52	4.80
IIIn & IIIm	35	13.80	5.12
IV & V	23	10.17	5.37
Total	83	12.11	5.32

(Kruskal Wallis ANOVA p = 0.04 sig)

The relationship between communication skills and other achievements

Scores for communication show a significant positive correlation with achievements in everyday living skills and with school attainments, as you can see in Table 4.9. These correlations mean that the better the teenagers ability to communicate, the higher their achievements tend to be in these other skill areas.

The communication scores show smaller positive correlations with the teenagers scores for friendship and leisure activities and this will be discussed further in the next chapter.

TABLE 4.9 - CORRELATIONS BETWEEN COMMUNICATION SCORES AND OTHER ACHIEVEMENT SCORES

	ELS	SAS	Leisure	Social Contact	Social Independence
Communication	0.54	0.58	0.32	0.25	0.28
	p> 0.001 sig	p> 0.001 sig	p=0.001 sig	p=0.008 sig	p=0.004 sig

As you can see in Table 4.10, there is a significant negative correlation between scores for communication and for difficult behaviour. This means that there is a tendency for the teenagers with poorer communication skills to show more behaviour problems. Although a correlation cannot explain the causal links, it seems most likely that poor communication leads to a lot of frustration which in turn leads to difficult behaviour. This is in line with findings from other studies such as that of Gath (1985) described in Chapter I.

TABLE 4.10 - CORRELATIONS BETWEEN COMMUNICATION SCORES, DIFFICULT BEHAVIOUR AND EFFECTS WITHIN THE FAMILY

	Difficult Behaviour	Family Attitude to Teenager	Effect on Family	Effect on Siblings
Communication	-0.26	-0.32	-0.27	-0.30
	p=0.006 sig	p=0.002 sig	p=0.008 sig	p=0.006 sig

The relationship between communication and family attitudes

Table 4.10 also shows that there are significant negative correlations between communication scores and several measures of the effect of the teenager within the family. Each family has been given a rating for their attitude towards the young person and for their views of the effect of the young person on the family as a whole and on the siblings in particular. These scores are explained in Chapter 10.

The correlations show that the poorer the teenagers communication scores, the less positive the family were about the young person. However, there are two ways of explaining this. It may be that the more progress the young person makes, the better the family feel about them as time goes on or it may be that if the family has always felt rather negative, they have spent less time helping the child. Only a longitudinal study following children from birth could resolve this issue.

Other studies

Cheseldine & Jeffree (1982) in their study of all severely mentally handicapped teenagers in Manchester, including those with Down's syndrome report findings confirming our own. Only 22% of their group of 214 could be clearly understood by others and could use appropriate language in all day to day situations. A further 45% had expressive language at a single word or short sentence level and could be understood by family or friends but not always by strangers. With regard to using spoken information, 16% of the young people were credited with the ability to remember and carry out a sequence of instructions, like a simple recipe or directions to a place, while 95% could respond to simple and familiar requests like "sit down" and "wash your hands".

Mittler and Preddy (1980) found that while 87% and 96% of school leavers from schools for those with severe learning difficulties were thought to be free of visual and auditory handicaps respectively, only 33% could speak in grammatical sentences and only one third of those with expressive language were intelligible to others. This again supports the data from our sample.

Carr & Hewett (1982) report that, for their group of 43 sixteen year olds, speech was said to be "good" in over a quarter, "quite good" in a further 46%. By contrast, two-thirds were said to have "good comprehension" and only 16% to "understand little". This is in agreement with the view often expressed by parents, who report that their children understand far more complex speech than they can produce.

When reporting on the same group at 21 years of age Carr found that the mean vocabulary age of her group assessed on the British Picture Vocabulary List was 52 months (a four to five year level). She found a significant difference between the language scores of those who had grown up at home (mean score 54 months) and those who had been boarded out (mean score 39 months) but not their IQ scores (means 46.6 and 40.4 respectively).

Carr also found that the boys were still significantly behind the girls on the language measure. The mean score for the 15 boys at 21 years of age was 45 months and for the 11 girls, 61 months. The boys were also behind the girls on the IQ measures at both 16 and 21. At sixteen the mean difference between the boys and girls on IQ scores was 8 points in favour of the girls, at 21 it was 10 points to the girls. (Interestingly, Carr reported some large individual gains in IQ between the ages of 16 and 21 although the young person had not usually changed their rank order in the group and the results of the IQ tests at 11 and 21 were very highly correlated ($r = 0.93$). Seven of her sample had increased their IQ scores by more than 10 points and three by more than 15 points).

Like us, Carr was able to look at the effects of social class. She found that the advantages of higher socio-economic status were significantly reflected in her measure of language, but not IQ.

It seems, then, that language development in this Down's syndrome group has been sensitive to factors in the home environment, as those children in care and those from disadvantaged homes are more delayed.

Shepperdson (1984) assessed her groups development on the Reynell Language Scale, the English Picture Vocabulary Test and the Gunzberg progress assessment charts. She found improvement with age and the advantageous effects of higher social class on both measures.

However, she did not find the significant sex diffferences reported by Carr & Hewett (1982) and Gath & Gumley (1984). In Shepperdson's first study (1972) there were no differences between the boys and girls, and she found this was still so in 1981 for this original sample, now in their teens.

Although Shepperdson found that for her total sample in 1981, the girls scored higher, she felt that this was because more of the girls happened to be in the higher social classes.

Summary and Conclusions

In this sample of ninety teenagers three (3%) had no speech at all. 18% of the younger girls, 33% of the younger boys and 10% of the older teenagers of both sexes are still communicating using phrases of three words or less in length.

40% of the younger teenagers use only keyword utterances such "Me go school?" or "Telly on please", which lack the normal grammar. For the older ones, 40% of the boys and 22% of the girls are still using only keywords.

Despite the teenagers limited communication skills, parents and teachers were good at understanding most of the young people. Some 10% were still having difficulty making themselves understood at home but in fact the majority were in difficulty out in the real world when trying to communicate with strangers. Less than half the girls and less than a fifth of the boys are able to talk successfully to strangers, according to their parents.

These results give us real concern if we begin to think through the implications of such limited communication for these teenagers. They will have great difficulty in leading ordinary lives in the community. Shopping, travelling on buses, buying a meal in a cafe and using a telephone will be difficult if not impossible for most of them.

Of course, some had quite good speech but they were a minority. Poor speech is a severe limit to social contact. How do you get to know someone and make friends if you cannot talk to each other? We will return to this issue in Chapter 6.

Poor speech may lead to emotional problems. How do you share your worries, or tell someone how you feel if you cannot talk adequately? Parents reported bedwetting, tantrums and even hair loss as ways of expressing anxiety.

Half the teenagers still engaged in fantasy worlds more typical of the normal four year old. Many had actual fantasy friends with names. In addition, emotionally disturbing experiences were still played out with dolls and play sessions. Many teenagers talked aloud to themselves in a way which seemed to be a form of self-instruction, suggesting that they are not easily able to internalise language and to think in silent speech.

These fantasy friends may be a substitute for real friends, especially as youngsters living with permanent companions their own age in care settings were less likely to have fantasy friends.

There is a relationship between difficult behaviour and the tendency to fantasy play which is not easy to interpret. The youngsters engaging in fantasy worlds and self-talk showed signficantly more difficult behaviour, may be as a way of expressing their frustration at not being able to fully participate in the social world of their age group.

When we looked for factors which have influenced the development of communication, our data show that for the sample as a whole the boys are more delayed and have more difficulty being understood than the girls. This is not easy to explain except in terms of genetic influence and it is a difference which is seen in normal children as well. The maximum score on our measure of communication was achieved by two boys compared to seven girls in the younger group and three boys and six girls in the older group. This is in contrast to the similar comparison for the top scores on every day living skills where the boys were in the lead. One word of caution - it is a significant finding and suggests that the boys may need more help but it is a finding that only has real significance when discussing groups. It does not mean that all boys are worse than all girls, so that it is important to explain the implications carefully to parents. It would be counterproductive if, aware of these findings, they expected less from their boys.

Fortunately the data showed that communication skills continue to improve with age for both sexes.

Adult attention seems to contribute significantly to progress where the teenagers are the only or the youngest child in the family, they were doing better than eldest and middle children.

The teenagers progress was also affected by the social class of their family, with those in the more disadvantaged families showing significantly slower progress.

Progress in other areas of achievement are correlated with progress in communication. Teenagers with better communication scores, were likely to have better achievements in everyday living and academic skills. Better communication was also reflected in more social contact and leisure activities and this is discussed further in Chapter 6. Those with poor communication had higher scores for difficult behaviour then those with good communication.

Finally, there were negative relationships between the way the family felt about the teenager and poor communication.

Families were less positive when the teenager was less able in communication, but this finding is difficult to interpret. The family may always have been less positive and therefore not spent so much time teaching the child as in the more positive families.

Clearly, all these findings suggest that commununication should be a priority area for intervention. Language teaching should be started in babyhood if it is to be maximum effect. However, we feel sure that these teenagers could all improve quite considerably given appropriate help.

There is an urgent need for more speech therapy to be available to this age group.

CHAPTER 5

ACHIEVEMENTS AT SCHOOL

In this chapter, we turn our attention to the teenagers achievements in the more academic areas of the school curriculum, reading, writing, arithmetic, money and general knowledge.

There is very little published research on the academic achievements of people with Down's syndrome. For a review of the literature to 1985, the reader might like to consult the chapter by Buckley in Lane and Stratford (1985).

In thinking about achievements in school, we have again tried to focus on those academic skills that we felt were the most important for the teenagers lives in the real world.

In the same way as most of us take for granted our ability to speak and communicate effectively with each other, we probably also take for granted our reading skills, our ability to use money, to write a letter and our knowledge of personal information and of the world around us. It is hard for most of us to imagine what life experience is like for those who can do none of these things.

Reading

The questions asked about reading were aimed at obtaining a view of the everyday reading skills of the young people.

For the girls 14 (77%) of the under 14's and 18 (81%) of the over 14's could read something. Comparable figures for the boys were 18 (64%) of the under 14's and 16 (22%) of the over 14's. However, the teenagers might only be able to read a few social sight words such as "ladies", "bus stop", or "school".

TABLE 5.1 - EXTENT OF THE READING SKILLS
(of the "readers")

		YES		WITH HELP		SOME TIMES		NO		NOT KNOWN	
		-14	+14	-14	+14	-14	+14	-14	+14	-14	+14
1 Can read sentences	G	92	77					8	23		
	B	77	87					23	13		
2 Can read books	G	71	72					29	28		
	B	50	68	7				50	25		
3 Reads n/paper daily	G	36	22				17	64	61		
	B	16	18			6	7	78	75		
4 Reads social sight vocab.	G	78	73				5	22	16		6
	B	77	81					23	12		7
5 Reads simple messages	G	36	38					64	56		6
	B	34	43				7	66	50		
6 Reads for pleasure	G	50	42					50	52		6
	B	45	37				7	55	56		

(Total sample of readers = 14 girls, 18 boys (Under 14)
18 girls, 16 boys (Over 14)

Of these "readers", just half in each group could read more than 50 words. Table 5.I gives a more useful indication of the extent of these reading skills of those who can read something.

While half the readers among the younger boys and 70% of the readers in the other three groups could read books, for the majority these books were simple early reading books.

Fifteen (I6%) could be described as quite good readers and read children's adventure books such as Famous Five, Secret Seven, simple nature books and books on sport.

Interestingly, many parents commented that teenagers often attempted to master the TV pages in the newspaper. If they did read papers, then TV, sport and pop stars were the topics of interest - like most other teenagers.

While up to half this group of fifteen could read for pleasure, among the whole group including non-readers, many parents commented on their children's love of books. They liked to be read to and to look at books. Six parents commented on the success of cassette tapes and books in helping their children learn to read.

When each teenager is given an overall score for their reading achievement, we found that the mean score for the boys was II.24 and for the girls I3.65. The girls are doing a little better but this difference is not large enough to be statistically significant.

There is some progress with age, the mean score for the under I4's being II.54 and for the over I4's, I3.II.

Later in the chapter, we discuss the influence of family position, social class and school on each of the school achievement scores we have looked at. You will see that achievement in reading is associated with the teenagers family position and social class. The teenagers in the lowest social class groups show the least progress in reading. This finding is similar to that for the school population as a whole. Those who are only or youngest children are doing better than those who are eldest or middle children. So, here again it seems that the time adults can spend helping their youngsters is having a significant effect on their progress.

Only two other studies have reported on reading skills in teenagers of this age.

Carr & Hewett (I982) report that in their group of 43 sixteen year olds over half could not read more than a few words. Seven could read quite well and one of these had a Schonell Reading Age of II year 7 months. At 21 years of age, this same group were visited again. Only two fifths of them could score at all on the Neale test for Reading Ability.

Cheseldine & Jeffree (I982) report that in their group of all severely mentally handicapped teenagers including those with Down's syndrome, only 8% could read and act appropriately to signs giving directions in a shop or a street, but 75% could recognise their name when written down.

Drawing and Writing

Table 5.2 illustrates the answers to questions about the teenagers competence and interest in drawing and painting activities. Indeed many parents remarked on these as favourite leisure time activities as you will see in Chapter 6.

TABLE 5.2: ART SKILLS

QUESTION		YES		NO		SOMETIMES	
		-14	+14	-14	+14	-14	+14
1 Can use crayon	G	94	100	6	-		
	B	92	95	8	5		
2 Can use chalk	G	94	95	6	5		
	B	92	81	8	19		
3 Can use Felt-tip	G	94	95	6	5		
	B	92	91	8	9		
4 Can use ink-pen	G	50	50	50	50		
	B	92	54	8	46		
5 Can use paint-brush	G	94	95	6	5		
	B	96	95	4	5		
6 Enjoys drawing	G	100	86	-	14		
	B	82	54	14	27	4	19
7 Enjoys colouring	G	100	100	-	-		
	B	82	86	14	9	4	5
8 Enjoys painting	G	94	95	6	5		
	B	79	60	17	31	4	9
9 Can use scissors	G	88	82	12	9		
	B	75	72	11	19	4	4
10 Can cut out a picture	G	61	81	22	19	17	
	B	68	68	35	32	4	4
11 Other art interests	G	72	45	28	50		5
	B	28	32	57	68	15	

It shows that all but the most profoundly handicapped could use crayons, chalks, felt tips and paints and enjoyed drawing, colouring and painting.

Table 5.3 summarises the answers to questions about practical writing skills.

TABLE 5.3 - WRITING SKILLS

QUESTION		YES		NO		WITH HELP	
		-14	+14	-14	+14	-14	+14
1 Can trace over letter/word	G	83	91	17	9		
	B	89	91	11	9		
2 Can copy letter/ word	G	77	91	23	9		
	B	92	77	8	23		
3 Can write own name	G	72	72	28	28		
	B	68	68	28	32		
4 Can write own address	G	16	31	78	60	6	9
	B	14	28	82	72	4	
5 Can write family names	G	50	36	50	59		5
	B	21	28	71	72	8	
6 Can write a simple sentence	G	17	22	67	73	16	5
	B	14	28	82	72	4	
7 Can write a simple message	G	6	22	83	73	11	5
	B	7	14	89	86	4	
8 Can write simple stories	G	6	19	89	81	5	
	B	4	9	96	91		
9 Can write a short letter	G	12	19	71	81	16	
	B	8	14	85	86	7	

While most teenagers could copy and write their own names, few had any useful spontaneous writing skills. Even among the older ones, less than a third could write down their address or family names.

For all practical purposes, then, the majority of teenagers have no useful writing skills at all. This must be an area which should be given much greater attention from the earliest school days.

In the Cheseldine & Jeffree (1982) sample 42% of the group could write their first name without any help. None of the other studies report on the teenagers' writing abilities.

When the teenagers were given an overall score for their achievements in writing, they were uniformly poor. There is no significant difference between the boys and the girls (mean scores are boys 6.92 and girls 7.86) and only a small improvement with age (under 14's 6.83, over 14's 7.89).

General knowledge

Here again we asked about aspects of general knowledge that we felt were relevant to everyday living, as you can see in Table 5.4 and 5.5.

While the questions only sample a limited and quite superficial range of knowledge, time and personal information seemed to us to be areas of relevance, as did words to describe the weather. The passage of time and the state of the weather are important everyday experiences. If you have little grasp of them, or limited means of expressing the experience you are going to be considerably hampered.

Most of us orientate ourselves by knowing the time and the day of the week. It's hard to imagine how we would feel if we had no understanding of the progression of the days of the week, or no conception of time or of the progression of months and seasons of the year.

How would we feel about our own selves and identity if we were unable to say our names, where we live, how old we are or when our birthday is?

TABLE 5.4 - GENERAL KNOWLEDGE

QUESTION		YES		NO		PARTIALLY	
		-14	+14	-14	+14	-14	+14
1 Can name days of week	G	45	73	44	22	11	5
	B	53	55	47	36		9
2 Can name months of year	G	12	32	77	68	11	
	B	21	36	75	50	4	14
3 Can say own age	G	77	91	23	9		
	B	75	81	25	19		
4 Can say own name	G	83	95	17	5		
	B	92	86	8	14		
5 Can say own address	G	67	86	27	14	6	
	B	57	64	36	31	7	5
6 Can say own birthday	G	50	63	44	37	6	
	B	35	64	61	31	4	5
7 Can tell the time	G	12	19	55	50	33	31
	B	15	19	64	45	21	36

You can see from the Table, that four out of five older boys and nine of of ten older girls could say their name and age correctly, with the younger age group a little behind on knowing their age.

Most of the older girls, four out of five, knew their address but this figure drops to a little more than half for the boys and younger girls. Put the other way around, nearly half the young people would not be able to tell anyone where they lived if they were lost.

Just two thirds of the older teenagers can say when their birthday is compared to less than half of the younger ones.

Half the young people had no ability to tell the time at all, one in five of the older ones were able to do so to a useful extent, the remainder were beginning to grasp the hours and half-hours. Some were using digital rather than traditional clocks.

Three-quarters of the older girls could name the days of the week in the correct order but half or less of those in the other three groups. Very few of the younger ones and only a third of the older ones knew the months of the year in order.

When we reflected on everyday knowledge and its importance, we realised that the weather loomed large. Not only is it the most common topic of casual conversation when greeting acquaintainces, it is a powerful experience, shaping our daily behaviour and dress. So we wondered how adequately these teenagers could describe the range of weather they experience.

Table 5.5 illustrates the extent of use of common words for the state of the weather. The questions asked if the teenager used each of the words to describe the weather.

TABLE 5.5: WORDS USED TO DESCRIBE THE WEATHER

QUESTION		YES		NO	
		-14	+14	-14	+14
Sunny	G	72	91	28	9
	B	75	72	25	28
Thunder	G	50	86	50	14
	B	67	68	33	32
Cold	G	77	95	23	5
	B	67	86	33	14
Wet	G	50	81	50	19
	B	71	68	29	32
Raining	G	94	95	6	5
	B	85	86	15	14
Windy	G	55	77	45	23
	B	53	63	47	37
Hot	G	66	91	34	9
	B	60	77	40	23
Dry	G	45	46	55	54
	B	40	54	60	46
Other	G	39	23	61	77
	B	36	37	64	63

As you can see from the figures most of the young people were familiar with most of these words and able to use them and that there is clear improvement with age and less difference between boys and girls than for some other areas.

(6)

When the teenagers were given an overall score for their general knowledge, we were able to show that there was not a significant difference between the achievement of the boys and girls in this area (mean scores were boys 21.62 and girls 23.36) but there was significant improvement for the whole group as they got older. The mean score for the under 14's was 20.43 and for the over 14's, it was 24.45.

In the Cheseldine & Jeffree study, while 73% appreciated the difference between weekdays and weekends, as shown by their different behaviour in activities like rising and dressing, only 35% could tell the hour on the clock and just 12% could tell the time in hours and minutes.

The other research studies do not report any data on teenager's general knowledge.

Number and Money Skills

The questions in this section attempted to elicit an overview of the range of number skills and money skills achieved by the teenagers.

First we asked about knowledge of numbers and counting. As you can see in Table 5.6 only 22% of the younger girls, 25% of the younger boys, 45% of the older girls and 54% of the older boys could recite the numerals in correct order beyond 1 to 20.

TABLE 5.6 - NUMBERS AND COUNTING

		None		0 - 5		0 - 10		0 - 20		0 - 50		0 - 100	
		-14	+14	-14	+14	-14	+14	-14	+14	-14	+14	-14	+14
Can recite numbers to	F	6		22	9	22	9	28	37	11	18	11	27
	M		9	11	5	25	9	39	23	11	18	14	36
		None		0 - 5		0 - 10		0 - 15		0 - 20		20+	
Can count objects to	F	11		11	14	22	14	11	4	39	32	6	27
	M	3	14	11	4	25	18	11	5	36	32	14	27

Only 6% of the younger girls, 14% of the younger boys and 27% of each of the older groups could actually count more than 20 objects correctly. Table 5.7 gives an indication of achievements at simple arithmetic.

TABLE 5.7 - ACHIEVEMENTS IN SIMPLE ARITHMETIC

		YES		NO		WITH HELP		SOME TIMES	
		-14	+14	-14	+14	-14	+14	-14	+14
Can do simple addition	F	45	59	55	41				
	M	43	59	53	36	4			5*
Simple subtraction	F	28	37	66	63			6	
	M	22	32	75	63			3	5*
Simple Multiplication	F	6(1)	9(2)	94	91				
	M	4(1)	5(1)	94	90				5*
Simple Division	F	6(1)	5(1)	94	95				
	M	4(1)		96	96				4*

* Don't know

While around half of the teenagers can do some simple addition mainly of numbers under ten and about a third can do simple subtraction, only 5 teenagers in the whole group of 90 could do any simple multiplication and only 3 divide.

A number of authors suggest that number concepts seem particularly difficult for children with Down's syndrome and certainly our data suggest that this is true.

In terms of the everyday use of number, we felt being able to count small quantities and of course, being able to count money were the most relevant.

First we asked how many of the coins and notes the young people could recognise and name.

Of the younger children 33% of the girls and 36% of the boys could not recognise or name any coins or notes at all. For the older children the figure was 41% for both sexes.

Only 2 of the younger girls and 3 in each of the other groups could recognise all the coins and notes we use.

It is therefore not surprising that when we come to looking at the practical use of money we see a rather gloomy picture.

Table 5.8 summarises the answers to the questions on using money.

TABLE 5.8 - MONEY

		YES		NO		WITH HELP	
		-14	+14	-14	+14	-14	+14
1 Can count out simple amounts	F	28	41	66	54	6	5
	M	18	23	82	68		9
2 Can give appropriate money in shop	F		19	100	72		9
	M	4		82	96	14	4
3 Relies on shop assistant to take correct money	F	100	96		4		
	M	93	96	7	4		

Of the younger children only 28% of the girls and 18% of the boys could count out simple amounts of money, while for the older children the figures were 41% for the girls and 23% for the boys. The girls seem to be a little ahead but you can see from the answers to the next question that only 4 (11%) of the older girls and 1 (4%) younger boy could actually count money sufficiently well to manage in a shop.

Like the achievements in useful writing skills, achievements in arithmetic and money skills are depressing. Most of the teenagers have no useful level of skill at all.

When we rated each teenager's arithmetic and money skills we found that the boys and girls were equally poor as can be seen from Table 5.9.

TABLE 5.9 - MEAN SCORE FOR ARITHMETIC AND MONEY SKILLS IN RELATION TO SEX AND AGE

	N	Mean score Arithmetic	Mean score Money
Boys	50	7.6	7.84
Girls	40	8.01	8.63
Under 14	44	7.00	6.65
Over 14	46	8.60	9.79

(no significant difference)

There is some evidence of improvement with age on both scores. The improvement in money skills particularly is encouraging but not enough to make much difference in practice.

Other studies
With regard to number skills Carr & Hewett (1982) report that two thirds of their sixteen year olds could recognise numbers and count. Less than half could add single numbers, less than a quarter could do subtraction and only 2 could multiply or divide. At twenty-one years of age, more than half could count but only two could handle addition and subtraction of more than 2 figure numbers.

With regard to money skills Cheseldine & Jeffree (1982) report that only 6% of their group could combine coins and notes to give a specified sum of money and 17% knew some equivalent values, ie that two 50p pieces = £1. 56% could pick out by name coins such as 50p, 10p and 2p pieces. Few of their teenagers had much real practise with money. 59% received pocket money for specific purchases only, with 28% having weekly pocket money to spend as they please. (In our sample 55% received pocket money and Shepperdson reports a very similar figure for her group)

School Achievements Scores (SAS)
In the same way as for every-day living scores, we gave the teenagers scores based on their individual achievement in each area of school achievement that we looked at, ie scores for achievement in reading, writing, arithmetic, money and general knowledge. We then added these to give each teenager a total score for school achievement (SAS).

We were then able to look at factors which might be influencing the teenagers progress in these areas, in the same way as we have done for everyday living skills.

Effects of Sex and Age
While the mean SAS score for the girls is 61.54 and for the boys 55.22, this difference is not large enough to be significantly different.

Similarly, while there is an improvement with age (mean score under 14 = 52.46, Over 14 = 63.85) this again is not large enough to achieve statistical significance.

Effect of Family Position
The effect of the young person's position in the family on all school achievement scores can be seen in Table 5.10.

TABLE 5.10 - ALL SCHOOL ACHIEVEMENT SCORES IN RELATION TO FAMILY POSITION

Family Position	Reading	Writing	Arithmetic	Money	General Knowledge	Total School Achievement
Only	16.62	8.38	9.69	9.87	26.62	71.19
Eldest	11.14	7.09	7.26	8.00	20.38	53.88
Middle	8.20	5.40	7.50	6.60	17.80	45.50
Youngest	13.42	7.69	7.78	8.19	24.30	61.38
	p=0.27	p=0.45	p=0.87	p=0.86	p=0.07	p=0.39
	ns	ns	ns	ns	ns	ns

While the differences do not reach statistical significance, you can see that the effects are in the same order as for communication and everyday living scores. The only children are the highest achievers, followed by youngest and eldest children. The middle children are making the slowest progress. These differences according to family position are most marked for reading achievement and then general knowledge. Achievements for writing, arithmetic and money are extremely poor for everyone.

Effect of Social Class

The effect of the social class of the family on the young persons' school achievements are shown in Table 5.11.

TABLE 5.11 - ALL SCHOOL ACHIEVEMENT SCORES IN RELATION TO SOCIAL CLASS

Group	N	Reading	Writing	Arithmetic	Money	General Knowledge	Total School Achievement
I & II	25	15.44	8.08	8.92	9.12	24.16	65.72
III	35	14.91	7.94	9.20	10.54	24.80	67.40
IV & V	23	6.56	5.96	5.24	4.87	16.44	39.06
	83	12.76	7.43	8.01	8.54	22.29	59.04
		p= 0.01	p=0.08	p=0.01*	p=0.04*	p= 0.01	p= 0.01*
		sig	ns	sig	sig	sig	sig

(Kruskal-Wallis ANOVA see Appendix)

You can see quite clearly that the youngsters in the lower social class families are lagging way behind in school achievement, especially in the area of reading but all areas are affected.

As suggested earlier, these families are likely to suffer from a variety of disadvantages, including relative poverty and poorer housing.

These disadvantages are known to affect the school progress of all children, so that in this respect our children with Down's syndrome are as sensitive to good and poor environments as normal children.

Are all schools equally effective?

It is quite reasonable to suggest that some schools provide better learning environments than others. Schools vary in the quality of the physical environment, the quality and enthusiasm of teachers and their approach to the curriculum for slow learners.

The young people in the sample were in some sixteen schools throughout Hampshire and in many cases there were only one or two children in any one school. However, there were eleven or more teenagers in each of five schools for children with severe learning difficulties, so we analysed the data for these five schools. Table 5.12 shows the mean total school achievement scores for the five schools. Although the mean score for some schools is clearly higher than others the difference between the mean scores for the schools does not reach statistical significance.

TABLE 5.12- SCHOOL ACHIEVEMENT SCORES (SAS) FOR THE TEENAGERS IN THE MAIN 5 SCHOOLS

School	No of Children	SAS Mean Scores	Range
1	11	66.09	1.00 - 103.00
2	11	45.77	6.00 - 105.00
3	13	62.04	29.50 - 101.00
4	13	49.92	6.50 - 99.00
5	13	51.96	0.00 - 132.00
1-5	61	55.16	0.00 - 132.00

(see Appendix for statistical analysis p = 0.54 ns)

Table 5.13 shows the mean scores for the children in each school for school achievement, everyday living skills, communication and difficult behaviour and here we begin to see some interesting trends. The figures in brackets give the rank position of the schools for each skill area.

TABLE 5.13-

MEAN SCORES FOR SCHOOL ACHIEVEMENT, EVERYDAY LIVING SKILL, COMMUNICATION AND DIFFICULT BEHAVIOUR FOR TEENAGERS IN THE 5 MAIN SCHOOLS
(Rank position in brackets)

School	No of Children	SAS	ELS	COMM	D.BEH
1	11	66.09(1)	91.90(4)	10.0(5)	9.91(4)
2	11	45.77(5)	97.55(3)	10.9(3)	8.09(3)
3	13	62.06(2)	100.46(1)	13.77(1)	5.85(1)
4	13	49.92(4)	98.38(2)	12.61(2)	6.92(2)
5	13	51.96(3) (p=0.54ns)	71.23(5) (p= 0.01 *sig)	10.76(4)	10.85(5) (p=0.04 *sig)

(see statistical analysis in Appendix)

If you look at this Table, you can see that there is remarkable consistency in the last three columns.

In school 3, the youngsters have the highest ELS scores, the best communication skills, the least difficult behaviour and the second highest scores on the school achievement skills.

Across all the schools, the better the everyday living skills, the better are the communication achievements and general behaviour. School achievement scores are more variable and less clearly related to the communication and difficult behaviour scores.

School 3 is clearly achieving the best overall results and school 5 the poorest.

The teenagers in school 5 have the poorest everyday living skills and poorest behaviour, they are second to bottom on communication and third on school achievement. Curiously, the youngesters in school I, have the highest score for school achievement, yet are fourth for Everyday Living Skills and poor behaviour and worst on communication.

We tend to feel that the scores for ELS, communication and difficult behaviour are more robust and meaningful than those for school achievement for the following reason. The range of achievement across the sample in the everyday living skills and communication is very wide and reflected in wide differences in daily performance. For the skills sampled under school achievement the attainments of the sample, ie reading, writing, money and general knowledge are all extremely poor and the actual range of differences across the teenagers rather small, except amongst the brightest children and the brightest children are not in these five schools. They are mostly in schools for moderate learning difficulties.

It is clear from our data that the teenagers in some schools are doing significantly better than others. School 3 is clearly producing better results than Schools I and 5. As you can see from Table 5.I4 these differences cannot be explained by any differences in the socio-economic status of the children in the different schools.

It would seem to be a real difference attributable to the quality of the learning environment being provided in the schools.

TABLE 5.14 - SOCIAL CLASS DISTRIBUTION WITHIN SCHOOLS

School	N	I & II	III	IV & V
0	10	5	2	3
1	10	5	3	2
3	13	3	6	4
4	12	2	6	4
5	13	4	5	4

(chi sq p = 0.77 n.s)

Summary

While there are a few teenagers in the group with really useful levels of reading skill, able to write messages and short notes and to manage simple arithmetic, most of these young people have not attained sufficient skills in any of these areas to be of much practical use to them.

Fifteen (16%) of the young people could read well enough to be able to read a story book or the newspaper. Many parents reported that reading was not being taught at school, though we have no accurate figures to allow us to divide the non-readers into those who had been introduced to reading but made no progress and those who had never had a chance to learn.

Progress in reading showed the same relationship to family factors as it does in ordinary children. Those whose parent probably had more time to spend with them (the only and youngest children) and those in the higher social class groups were more advanced with their reading.

There is an increasing amount of evidence to suggest that reading is an area where a significant number of children with Down's syndrome are able to make more progress than is often assumed. The teaching of reading can be used as an aid to language learning. This is an approach which has been used successfully for many years with other groups of language delayed and disordered children (Hutt,1986). While at present reading research focuses on the young child, there is no reason to suppose that teenagers cannot continue to make progress in reading with appropriately structured methods. Such reading, if based on appropriately chosen vocabulary, grammar and syntax might well lead to improved speech in the teenagers and is certainly an area which needs to be researched. Reading practise, in the authors experience, can improve articulation and give the youngsters practice in using sentences which are grammatically correct but not yet part of their usual spoken repertoire.

When we look at our results for drawing and writing skills, we find that drawing is an extremely popular activity.

However writing skills were very poor. The majority could not even write their address or family names. Their poor writing progress is partly a function of poor fine motor skills, but we suspect it could be improved considerably if practice was given from pre-school days. There are individuals known to the authors who have learned to type and in these days of home computers, this is an avenue which should be explored.

When we turn to the teenagers range of general knowledge about themselves and their world we find that the majority of the older group can say their name and age correctly, some 65% could say their address and their birthday. All these figures were less for the younger children. Over half of the older group could name the days of the week but only a third could name the months of the year. Less than one in five (19%) of the older children could tell the time from a digital clock and very few from a traditional clock face.

When we consider achievements in the area of number and money skills, this rather depressing picture continues. Only 27% of the older teenagers could count up to 20 objects correctly. Half could do some simple additions of numbers under 10, about a third some simple subtractions, only 5 teenagers could do any multiplications and 3 some simple division.

Some of the teenagers could count small amounts of money but only five could give correct amounts of money in a shop. Most of the teenagers had no useful knowledge of money at all and could not even name all the common coins, though some 55% received pocket money to spend.

Very few of these young people have any useful reading, writing or number skills.

In the last part of the chapter, factors influencing the progress of the teenagers in these skill areas are considered. Although the boys are a bit behind the girls, the differences between them are not large enough to be statistically significant and there is evidence of improvement in all areas with age.

Family position has a small effect with only and youngest children achieving more than eldest and middle children.

The social class of the family has a significant effect on all areas of progress, particularly reading, arithmetic, and general knowledge. The teenagers in the lowest social class group are the most disadvantaged.

Finally, schools make a difference. Some schools are achieving higher standards than others. Not only do our data show significant differences in the level of everyday living skills and communication skills attained by the children in different schools, they also show significant differences in the amount of behavioural problems in different schools. The schools with higher achievement levels in the range of skills we looked also had young people with better communication levels and fewer behaviour problems.

CHAPTER 6

SOCIAL ACTIVITIES, LEISURE AND FRIENDSHIPS

Adolescence is the time when for most teenagers, friends become more important than family and much more leisure time is spent in the company of friends of one's own age. The teenager is becoming an independent adult, establishing his values, beliefs and self-identify. Deciding who he is, what he wants to be and where he wants to go in the world. It is a time for exploring one's skills, interests and deciding on an occupation. It is a time for exploring relationships and determining one's personal and sexual identity.

In all this, a teenagers social life, his leisure activities and friendships are of crucial influence and importance if he is to move towards becoming a well-adjusted and independent adult. We develop our own identity, decide what sort of person we are and want to be, by comparing ourselves with others, appraising our skills and achievements and setting appropriate goals when we see ourselves and our successes and failures in comparison with our own age-group. If a person with a handicap is to take his or her place in society then they must also go through this often painful experience, learning as we all have to, what their limitations are and to make a realistic and healthy adjustment to life, despite these shortcomings. They also need the opportunity to seek out and sustain friendships - real friendships based on mutual warmth and respect to enable them to grow as people and to value themselves.

Leisure interests

The first aspect of the teenagers social life we asked about was how they used their leisure time at home. The results are summarised in Table 6.I.

It is clear that the most popular activities are watching TV and listening to pop-music since over 70% of our older teenagers do these things often. Outdoor activities, playing in the garden or riding a bike were only engaged in often by a third or less of the teenagers. The older teenagers were less likely to play outside than the younger ones and this would seem to be a normal teenage progression.

The boys of all ages were more likely than the girls to ride bikes often, though even so, bike riding was only a regular activity for 30% of the boys and 10% of the girls.

Drawing, doing jigsaws and playing games with other members of the family were very popular. About half the teenagers did these sometimes and another third, often.

Reading was a regular leisure activity for less than one in five. Not much of the teenagers time was being spent on helping with chores. Very few did chores often, though more than threequarters did sometimes.

In Shepperdsons (1984) study, 19% of the teenagers "often" helped in the house with common tasks such as making beds and cleaning. 36% rarely or never helped with chores.

Contrast this with Anderson and Clarkes report that 69% of their group of normal teenagers regularly did two or more chores in the home, but only 32% of the physically handicapped group.

QUESTION		OFTEN		SOME TIMES		NEVER	
		-14	+14	-14	+14	-14	+14
1 Listens to pop music	G	61	73	33	27	6	
	B	47	73	46	23	7	4
2 Watches TV	G	67	73	33	23		4
	B	93	77	7	18		5
3 Helps with chores	G	28	14	67	77	5	9
	B	4	5	93	77	3	18
4 Plays in garden	G	33	23	50	54	17	23
	B	39	23	57	63	4	14
5 Riding a bike	G	11	9	33	27	56	64
	B	29	36	39	23	32	41
6 Reading	G	11	23	44	23	45	54
	B	18	14	25	41	57	45
7 Playing games	G	44	32	50	54	6	14
	B	32	23	57	54	11	23
8 Drawing	G	39	45	61	55		
	B	36	9	50	64	14	27
9 Jigsaws	G	39	27	44	37	17	36
	B	25	18	50	23	25	59
10 Other	G	39	32	17	9	44	59
	B	43	36	3	18	54	46

TABLE 6.1- FAVOURITE LEISURE ACTIVITIES

Table 6.2. shows the activities these teenagers had a particular interest in even though this might be a passive interest. Pop-stars, pop-music and sport are the most popular suggesting pretty normal teenage awareness, despite their handicap. Some 70% of the teenagers were interested in these three. Only a third of the boys and even fewer girls were interested in the cinema. Just over a third of the girls but rather less of the boys were interested in fashion.

QUESTION		YES		NO	
		-14	+14	-14	+14
Has special interest in					
1 Cinema	G	17	14	83	86
	B	32	32	68	68
2 Pop Stars	G	61	59	39	41
	B	43	68	57	32
3 Pop Music	G	72	95	28	5
	B	57	91	43	9
4 Fashion	G	39	36	61	64
	B	11	23	89	77
5 Sports	G	67	59	33	41
	B	68	68	32	32

TABLE 6.2 - THE TEENAGERS PARTICULAR INTERESTS

Table 6.3 shows the competence acquired by the young people in operating the appliances most of us take for granted as necessities of everyday living. The results show the teenagers are really surprisingly competent with these leisure gadgets.

TABLE 6.3 - SKILLS AT USING TV RADIO ETC

QUESTION		YES		NO	
		-14	+14	-14	+14
Can operate					
1 TV	G	94	95	6	5
	B	89	95	11	5
2 Radio	G	83	86	17	14
	B	82	82	18	18
3 Record Player	G	67	86	33	14
	B	50	59	50	41
4 Tape Recorder	G	67	77	33	23
	B	61	73	39	27
5 Computer Games	G	28	64	72	36
	B	36	50	64	50

Other Studies

Carr & Hewett (1982) report that for their sixteen year olds, swimming was a prominent interest and that several were very good swimmers. One girl had a gold award for personal survival and wanted to train to be a pool attendent. Two boys had raised large sums of money with sponsored swims. Teenagers in their group enjoyed football, badminton, tennis, snooker, darts, cycling and horse-riding. Three liked music and one played an electric organ from music by number. Several enjoyed and were good at dancing. One lad was skilful at carpentry and had made himself two bookcases.

Anderson and Clarke (1982) in a study of physically handicapped teenagers, provides us with some useful comparative data as their handicapped teenagers were compared with a group of normal teenagers.

They found that for their normal teenagers, 48% watched TV for four or more evenings a week, compared to 70% of the physically handicapped teenagers. About the same number of the boys in each group (40%) enjoyed watching sport on TV and some 80% of both groups enjoyed indoor games at home. Reading was a popular occupation for the normal teenagers, 70% read the newpapers daily and 77% had read at least one book in the last month. Reading was less popular among the physically handicapped group. 90% of both groups enjoyed listening to music often. Swimming was a favourite pastime for the normal teenagers, only 10% of them never went swimming out of school. Other outdoor sports were also important as 70% of the normal teenagers played a sport outside of school.

Going to the cinemas is also a popular leisure activity among normal teenagers. In one study (Rutter,1979) nearly half the teenagers had been at least once in the previous month and a quarter had been 2 or more times.

Personal space
For most teenagers, personal space in their own room becomes important. They spend increasing periods of time on their own activities away from the family, either alone or with friends.

Table 6.4. summarises the answers to questions about the teenagers own rooms.

The majority of the teenagers, about three quarters, have their own room. At least half the teenagers are likely to be taking a pride in keeping it tidy, with the girls a little in the lead.

Over 70% of the girls are taking a pride in their room and putting up pictures and posters. The boys were as keen to put up pictures and posters but fewer were described as taking a pride in their rooms.

Not many of the teenagers made their own beds and for once, there are more boys (41% of the older ones) than girls (31%) making their beds regularly.

TABLE 6.4 - TAKING A PRIDE IN BEDROOMS

QUESTION		YES		NO		SOME TIMES	
		-14	+14	-14	+14	-14	+14
1 Has own bedroom	G	78	64	22	36		
	B	50	77	50	23		
2 Makes bed	G	6	31	11	32	55	37
	B	18	41	39	13	21	27
3 Keeps bedroom tidy	G	61	68	39	32		
	B	46	59	54	41		
4 Takes pride in bedroom	G	67	77	33	23		
	B	39	55	61	45		
5 Puts up pictures/ posters	G	67	77	33	23		
	B	57	77	43	23		

At this time a pride in personal appearance also becomes important. Unfortunately we only thought to ask about this for the girls! 67% of the under 14's and 64% of the over 14's were defintely taking an interest in make-up and their appearance, though the remainder were not.

Friendships
We then turned out attention to friendships. 79% of the younger children and 64% of the older ones play with friends. However, of those with friends only 30% of the girls and just under half of the boys play with a friend daily. About 15% of the teenagers play with a friend about once a week. This means that half the girls and a third of the boys see a friend to share leisure activities together less than once a week.

Adolescence is the time when friends of one's own age become increasingly important as young people move away from the family and begin to establish their own independence and identity, so that this lack of friendship in our teenagers must be a cause for concern.

When we asked if these teenagers had any special friend, half the younger ones did but only a third of the older ones. To be precise, 64% of the older girls and 73% of the older boys had no special friend at all.

A quarter had friends met at home, but about a third had only friends met at school and the remaining group (about 40%) had friends from both home and school.

A third of the children had only other handicapped children as friends. Around a third of the teenagers had normal friends only. The remaining third had both normal and handicapped friends. This means that unless they had brothers and sisters, a third of this group of teenagers had no normal friends to mix with and learn from.

It seemed that the main source of company for the teenagers was their own brothers and sisters if they had any at home, bearing in mind that 10% are only children and are 54% the youngest in the family.

50% of the younger boys and girls, 45% of the older girls and 27% of the older boys play often with brothers and sisters. Around 25% of all ages played with brothers and sisters often but 22% of the younger group and 32% of the older girls and 46% of the older boys never played with siblings.

So, for many of these teenagers, their main companions are the family. They do not have a great many friends and tend to spend a great deal of time amusing themselves in largely passive activities.

Many parents were aware of increasing social isolation, as these quotes illustrate.

"She is more and more restricted socially as she gets older because she is not accepted as well by the other children in the street anymore. Most of her time is now spent indoors watching TV. This causes an awful lot of upset in the house when she sees my son going to different places."

"Up to about 2 years ago a number of local children were happy to include her in their play but they gradually outgrew her and there are no younger children in the neighbourhood to replace them."

Only one of the other studies of teenagers with Down's syndrome has looked at friendships and Shepperdsons (1984) findings support ours. She reports that few of her group had any real friends. Only three or four (of 53) had friendships that were comparable to those enjoyed by the normal population. Though 30% had some contact with other children at home, these were usually either other handicapped or younger children.

In Anderson & Clarkes' (1982) study, they devote a whole chapter to social life, leisure and friendships reflecting their view of their significance at adolescence and indeed throughout adult life.

In their study, 31% of the physically handicapped teenagers attending ordinary day schools saw no friends out of school. Only 3% of their normal teenage comparison group saw no friends. 20% of the handicapped group and 19% of the normal group saw at least one friend out of school. 37% of the handicapped group and 28% of the normal group saw 2 to 3 friends.

Only 11% of the handicapped group but 50% of the normal group saw three or more friends regularly.

Over 33% of the normal teenagers had seen two or three different friends in the last week, compared to only 14% of the handicapped group.

Parents in Anderson and Clarkes' study were asked how often their son or daughter had been out with friends of their own age in the last week. 43% of the teenagers with a physical handicap had not been out at all, compared with less than 20% of the normal teenagers, most of whom went out with friends several times each week.

When they considered special friends, they found that 38% of the handicapped teenagers had no special friend, compared to only 7% of the normal teenagers.

In Rutters (1979) study of ordinary teenagers, over 70% claimed to have a special friend, usually of the same sex and threequarters were on regular visiting terms with these friends. Less than 10% had had no peer contact in the previous week, and over half had at least three of more contacts with friends each week.

Compared to these figures for normal teenagers, it is clear that our teenagers with Down's syndrome are lacking friends of their own age and must be seen as lonely in this respect.

A few of our group did have a range of friendships that seemed normal for their age.

One young lady of twelve had numerous friends to play with each day. She was often invited to sleep overnight at the homes of various school friends and they came to stay with her. Often her normal brother was invited too so that he did not feel left out! "In one family they visit, there is also a younger brother of about the same age and here there is the usual boys versus girls rivalry and they seem to forget that the girls are mentally handicapped."

Another parent says "He has many friends, both normal and handicapped, with one special handicapped friend from school. He mixes well with the other children on the estate and is allowed to go out to play with them. He is particularly good at football. He also enjoys running and jumping."

These quotations from parents are sadly more typical.

As a parents of a 14 year old put it "Sarah's social life is almost non-existent compared to her normal sister's - just two years older. Her sister is always out visiting friends, going to the city by train to shop, to the cinema, swimming or even just popping into a Wimpy Bar. Sarah, on the other hand, has no local friends, is not allowed out alone and therefore her only social acitivity is her weekly visit to the Rainbow Club escorted both ways by her father. Her sister sometimes takes her on walks with a group of friends."

"... if it wasn't for his brothers, Andrew would have a very lonely home-life."

"Her friendships from the early years have continued, although are somewhat different now that the other children have outgrown her and so treat Anne more as a younger child than as an equal. However, her relationship with one special normal friend has flourished. The two are now pen-friends, though see each other 3 or 4 times a year for holidays. When they are together Anne seems to behave much more independently and her speech improves. This

friend is just 15 months younger."

Independence at home
Few of the young people could be left alone in the house. Even those who could, few were left unsupervised for more than an hour, as you can see from Table 6.5.

TABLE 6.5 - INDEPENDENCE AT HOME

QUESTION		NOT AT ALL		LESS THAN 1 HR		MORE THAN 1 HR	
		-14	+14	-14	+14	-14	+14
Can child be left alone in house	G	89	27	11	50		23
	B	75	45	14	32	11	23

Parents reported that about four out of five of the younger teenagers could not be left alone in the home at all. About one in ten could be left for periods of less than an hour and for the boys, a few could be left a little longer.

There is some improvement with age and for the older group, parents felt able to leave over half of the boys and three quarters of the girls for periods of an hour or so.

One in four of the older teenagers could be safely left for more than an hour, but at the same time, a quarter of the girls and nearly half the boys could still not be left alone at all.

Our results are a little better than those reported by Shepperdson (1984). In her group of teenagers, no child could be left in the house for any length of time. Parents in her study reported that 38% could be left but, for half of these they would only feel able to leave them for 15 minutes or less - just long enough to pop to the local shop or to a neighbour.

Shepperdson does emphasise the wide variation again, when discussing this issue. There were one or two really independent teenagers. One was able to look after herself while her mother was at work on Saturdays, including being able to get up, dress, have breakfast, carry out jobs left on a written list by her mother and then ring her mother at work if she asked. But sadly this was as atypical in Shepperdson's group as in ours.

Carr & Hewett (1982) report that 12 (28%) of their teenagers could sometimes be left alone in the house, 8 of these for up to an hour.

Independence outside the home
We finally asked about activities outside the home and in the holidays. These results are summarised in Table 6.6 and 6.7.

TABLE 6.6 - ACTIVITIES OUTSIDE THE HOME

QUESTION		YES		NO		SOME TIMES	
		-14	+14	-14	+14	-14	+14
1 Can go to shop alone	G	11	23	89	77		
	B	21	41	79	59		
2 Crosses road alone	G	17	32	83	59		9
	B	32	41	64	55	4	4
3 Walks to school bus alone	G	22	45	72	55	Partly 6	-
	B	25	45	75	50	-	5
4 Has pocket money	G	56	64	33	36	11	-
	B	50	55	50	36	-	9
5 Belongs to normal club	G	22	23	78	77		
	B	32	23	68	77		
6 Belongs to handicap club	G	44	45	56	55		
	B	57	55	43	45		
7 Attends a playscheme in the holidays	G	28	27	67	73	5	-
	B	39	45	61	46	-	9
8 Any activities without relative	G	44	41	56	59		
	B	39	36	57	64	4	-
9 Most activities Independent of family	G	11	18	89	82		
	B	11	5	89	95		

TABLE 6.7 - PARTY-GOING

QUESTION		YES		NO		SOME TIMES	
		-14	+14	-14	+14	-14	+14
1 Invited to parties/ discos	G	89	91	11	4		5
	B	86	73	14	27		
2 *Frequency of discos/ parties		Weekly		Monthly		Annual	
	G	6	5	31	60	63	35
	B	8	25	67	50	25	19
3 +Type of disco/party		Normal		H/cap		Both	
	G	7	5	29	52	64	43
	B	8	6	42	56	42	38

* N = 16, 20 N = 24, 16

\+ N = 14, 21 N = 24, 16

When we looked at the teenagers competence in the skills necessary to go about the neighbourhood safely, you can see from Table 6.6 that many of the teenagers do not have the necessary competence.

Except for the older boys, less than one in four can go alone to a nearby shop. 40% of the older boys could do so. This may be the reason why only just over half of the group received pocket money. (Shepperdson (1984) reports an almost identical figure of only 58% of her teenagers receiving regular pocket money.)

About one third of the older teenagers can cross the road alone, and this usually meant only quiet roads that they were familiar with.

Nearly half of the older children could walk to the school bus and back home again on their own, especially if there were no roads to cross.

There were a few teenagers whose independence outside the home was approaching normal for their age:

One lad aged 14, cycles to the library and to friends homes by himself. He belongs to the local Scout troop and walks there by himself each week. Although he was last on a 3 mile trek with the Scouts and always lagging behind because he tires easily, overall he is seen as an asset to the group because of his friendly, cheerful disposition. In the school holidays he goes to Scout Camp and visits relatives in Ireland, travelling unaccompanied on the plane.

Another lad, having accompanied his brother on his brother's paper round on two consecutive days, crept out of the house on the next day (his brother's day off) cycled to the paper shop, collected the papers and delivered them. He was only discovered when the newsagent rang his parents as he had a few customers complaining that they had received the wrong papers!

In Shepperdsons (1984) study, 55% of the teenagers were never allowed out on their own at any time and our data for our older age group are very similar (50% or more do not go to the shops, cross roads or walk to the school bus, Table 6.6).

In Shepperdson's group only four had anything approaching the freedom of movement of the average teenager and even they could not use public transport. Only 44% went outside alone at all. Two boys went out on bikes, one not far, but the other had been encouraged from his earliest days to show maximum independence and was able to be much freer. Indeed his mother did not always know where he had gone. She reports that most parents would have been pleased to encourage more independence had they known how to. In Carr & Hewett (1982) study 13(30%) went out on their own sometimes, mostly to play with the local group or to neighbours or local shops. One boy went regularly to swim at local baths on his bike and one girl to the cinema with a friend.

Going to clubs, discos and parties

As you can see in Table 6.6, less than a quarter of our teenagers belong to a club where they mix with ordinary teenagers and about half belong to clubs for handicapped teenagers. These clubs usually meet weekly.

In the holidays, about a quarter of the girls and about 40% of the boys attend a holiday playscheme. These are the only activities of this sort that these young people participate in.

When we look at party going and discos - Table 6.7 - we see that most of the young people do get invited to parties or discos, though some do not. Approximately one in ten of the younger teenagers never go to parties or discos, and one in four of the older lads. For those who do go, these are much more likely to be monthly or yearly events, than weekly events. Four teenagers

only go to discos for ordinary teenagers. Half the older teenagers only ever go to social events for the handicapped.

Some 40% of the older teenagers go to social events for both ordinary and handicapped teenagers.

In Shepperdson's study (1984) 36% were members of special clubs for the handicapped, 13% in clubs for normal teenagers and 51% in no club at all. Her figure of 51% for belonging to no club is very similar to the data for our group but overall more of our teenagers belong to clubs, approximately 25% belonging to normal ones and 50% to special clubs, some to both.

In Anderson and Clarke's (1982) study, a third of the ordinary teenagers belonged to one club, another 12% to two clubs and 3% more than 2 clubs but 55% belonged to none. This means that our teenagers are not much different from other teenagers in this respect. Anderson and Clarke found that their physically handicapped group in ordinary schools had the same extent of club membership as ordinary teenagers. When they asked about parties and discos, then twice as many of the ordinary teenagers (33%) had been to dances and discos in the last month as had handicapped teenagers (16%). Going to parties was also a much more common activity for the ordinary teenagers, over two thirds of whom had been to a party in the last year, compared with less than half of the handicapped young people. Most of the parties attended by the handicapped teenagers were mainly for adults or were supervised teenage parties and less than one quarter were unsupervised teenage parties; in contrast to the ordinary teenagers, two thirds of whom usually attended unsupervised teenage parties.

Dependence on families

If we return to our own data in Table 6.6 and look at the figures of the last two questions, we see just how dependent the teenagers are on their families for their social and leisure activities.

More than half (about 60%) do not engage in any activity without a relative and only about one in ten of our teenagers could claim that most of their activities were independent of the family.

Contrast this with figures from Rutter's study of ordinary teenagers. He reports that very few teenagers went out regularly with their parents, only 10% as often as once a week and one third never went out with them.

In Anderson and Clarke's (1982) study only 3% of ordinary teenagers regularly went out with their parents, compared to 25% of their physically handicapped children in ordinary schools, and 70% for handicapped children in special schools.

They point out that this pattern shows the disabled teenagers still have a social life similar to that of much younger children.

Shepperdson (1984) reports the same pattern for her teenage Down's syndrome group. Their social lives are largely determined by their parents. Parents often absorb the teenagers into their own way of life, taking them to visit relatives, to church, to the pub or club, to dances and on family outings. This might work quite well in some instances, even if it resulted in mainly adult company, but if the parents themselves had few social activities then the teenager may do nothing.

Some parents may concentrate on activities for the handicapped such as Gateway clubs and disabled swimming clubs. About 25% of her families deliberately provided activities which involved integration with normal teenagers.

The relationship of social competence to areas of life
After looking in detail at the results of these sections of the questionnaire, we scored the answers for each teenager to give scores for the range of leisure interests, the amount of social contact and amount of social independence each teenager showed.

The score for leisure interests reflects the range of leisure interests and activities the young person engages in. The score for social contact reflects the range of friendships and amount of social contact at clubs etc the young person reported.

The social independence score rated the young persons' competence at such skills as crossing roads alone, going to shops alone and the number of activities engaged in independent of the family.

The scores now enable us to look at factors which might influence this area of development in the same way as we have with everyday living skills, school achievements and communication.

Effects of sex and age
There are no significant differences between the boys and the girls on any of these measures as you can see in Table 6.8

TABLE 6.8 - MEAN SCORES FOR BOYS AND GIRLS FOR LEISURE ACTIVITIES, SOCIAL CONTACT AND SOCIAL INDEPENDENCE

	Leisure Activities	Social Contact	Social Independence
Boys	17.66	10.26	2.74
Girls	18.35	10.03	2.45

(no significant differences)

Table 6.9 shows the mean scores for the younger and older age groups. There is no significant increase with age for any of the scores. In fact, the mean scores for the range of leisure activities and for social contact actually show a small decrease for the older age group.

The score for social independence shows a small increase, suggesting some improvement in this area.

TABLE 6.9 - MEAN SCORES FOR UNDER 14's AND OVER 14's FOR LEISURE ACTIVITIES, SOCIAL CONTACT AND SOCIAL INDEPENDENCE

	Leisure Activities	Social Contact	Social Independence
Under 14	18.17	10.69	2.17
Over 14	17.75	9.59	3.06

(no significant differences)

Although the decrease in the social contact scores for the older age group is small, it does reflect what many parents told us. They often reported that their teenagers were becoming more isolated as they grew older. At eleven, twelve or thirteen they were still able to play out in the neighbourhood with younger children in group activities. However, as they grew older, they were not so welcome to join in and their local friends tended to increasingly neglect them.

TABLE 6.10 - CORRELATIONS BETWEEN THE SOCIAL SCORES AND OTHER SKILLS

	Everyday Living Score	School Achievement Score	Communication Score
Leisure Acitivites	0.46 p 0.001	0.62 p 0.001	0.32 p 0.001
Social Contact	0.36 p 0.001	0.33 p 0.001	0.25 p= 0.008
Social Independence	0.50 p 0.001	0.46 p 0.001	0.28 p= 0.004

(These correlations are all significant)

The effects of competence in other areas of development

The scores for the range of leisure activities for social contact and for social independence were positively correlated with the teenagers scores for everyday living skill and school achievement as you can see in Table 6.10. In other words, the more capable the teenagers tended to have a wider range of activities, more social contact and to be more socially independent.

The young persons competence in communication is also positively correlated with his scores on the social competence measures, as one might well expect. Poor communication is obviously a great barrier in all social activities and these correlations show that the teenagers with better communication will have better social lives.

The effect of social independence skills

TABLE 6.11 - INTERCORRELATIONS BETWEEN THE THREE SOCIAL MEASURES

	Social Contact	Social Independence
Leisure Activities	0.40 p 0.001	0.46 p 0.001
Social Contact	-	0.50 p 0.001

Table 6.II shows the correlations between the three social competence measures we have taken. You can see that there is a significant positive correlation between the range of leisure activities and social contact and social independence. The more socially independent the young person, the greater their range of leisure activities and the more social contacts they had.

TABLE 6.12 - CORRELATIONS BETWEEN THE SOCIAL SCORES, EFFECT IN THE FAMILY AND DIFFICULT BEHAVIOUR

	Family Attitude	Effect on family	Effect on siblings	Difficult behaviour
Leisure Activities	-0.24 p= 0.01*	-0.13 ns	-0.18 p= 0.06ns	-0.09 ns
Social Contact	-0.34 p= 0.001*	-0.25 p= 0.01*	-0.28 p= 0.008*	-0.09 ns
Social Independence	-0.25 p= 0.01*	-0.11 ns	-0.01 ns	-0.19 p= 0.03*

(*denotes statistical significance)

Family attitudes

Table 6.I2 shows the correlations between the three social competence measures, the difficult behaviour score and the ratings of the family effects.

The measure of the families attitude towards the child is negatively correlated with the three social scores. This means that the more positive the family were about the teenager, the higher their social scores. Unfortunately correlations tell us nothing about cause and effect. The family may feel more positive towards the young person because of their social competence, or it could be the reverse. The family which feels more positive may have made more effort to encourage and help the young person towards greater social competence.

The other correlation in the table suggests that the teenagers social competence has no effect on how the family rate their positive or negative influence on the family as a whole or on the siblings in particular.

Difficult behaviour

Social competence is also unaffected by difficult behaviour, which we find surprising. One might well expect difficult behaviour to have had a significant negative effect on these social measures but it does not seem to in our study. This may be because the type of difficult behaviour we found was not necessarily disruptive. Bedtime and sleep problems, nail biting or picking and occasional tantrums when thwarted probably do not affect social life greatly - the other main problem is swearing. In fact, we only asked parents about behaviour at home and it is quite possible that many of these difficult behaviours occur less often in social situations.

Environmental influences

We now turn to the influence of family position and social class on the teenagers social competence. Table 6.13 shows the effect of the teenagers position in the family and Table 6.14 shows the effect of the socio-economic status of the family.

TABLE 6.13 - THE EFFECT OF FAMILY POSITION ON SOCIAL COMPETENCIES

Family Position	N	Leisure	Social Contact	Social Independence
Only	8	18.44	10.50	1.88
Eldest	21	16.88	9.95	1.62
Middle	10	16.35	8.90	2.70
Youngest	43	19.20	10.39	3.37
	82	18.18 p=0.05*	10.11 p=0.76 ns	2.69 p=0.18 ns

TABLE 6.14 - THE EFFECT OF SOCIAL CLASS ON SOCIAL COMPETENCIES

Social Class	N	Leisure	Social Contact	Social Independence
I & II	25	19.50	12.60	3.16
III	35	18.60	9.03	2.48
IV & V	23	15.93	8.69	2.22
	83	18.13 p=0.03* sig	10.01 p= 0.01* sig	2.61 p= 0.28 ns

The family position effects shown in Table 6.13 are in the same direction as for the other achievement scores for leisure activities and social contact scores. The only children and youngest children are doing the best, followed by the oldest and then those in the middle of the family.

However, the same is not true of social independence. Here the youngest children are doing the best then the middle, only and eldest children.

However the differences between these groups are not large enough to be statistically significant except on the leisure scores.

The figures in Table 6.14 show that the social class of the family has had no significant influence on social independence, though scores do decrease across the groups. This advantage of the higher socioeconomic groups is large enough to be significant for the range of leisure activities and amount of social contact.

The advantage of higher social class is particularly obvious if you look at the social contact scores. The teenagers in the higher status families have more social contacts and more friends.

Summary

While our teenagers had quite a wide range of leisure interests, they tended to be rather passive and solitary activities, as they spent a lot of time watching TV, listening to pop-music or colouring. They were interested in the usual teenage interests including sport, pop-stars and pop-music, but less interested in the cinema. While our teenagers with Down's syndrome were interested in sport, they did not seem to have much opportunity to actually enjoy sport outside school, especially team games like football or cricket, or games requiring partners. This seems a shame as involvement in sports has so many advantages. In addition to keeping the teenagers fit and slim, playing in sports can provide the opportunity to make friends as the following quote from a parent illustrates.

"He is a very competent swimmer and has won several medals. He belongs to a swimming club and normal youth club both of which he attends weekly. He also enjoys football and horse-riding."

Three out of four teenagers had their own bedroom and many were taking a pride in keeping it tidy and personalising it with their own posters or pictures.

Our teenagers do not have the same amount of friends and social contact as ordinary teenagers. Very few had a special friend. Most relied almost entirely on their own family for company and as a group are very socially isolated from their own age-group outside the family.

Very few of our teenagers have acquired enough skills for parents to feel happy about leaving them alone in the house for more than very brief periods. For some, parents felt that they still needed constant supervision, but for others, although they could be trusted to occupy themselves and not get into mischief, they could not deal with any emergencies, nor answer the door or telephone.

Very few of teenagers have acquired enough competence to go about the neighbourhood independently. More than two thirds could not cross roads safely and less than a quarter could go to the local shop alone. Put alongside the findings reported in Chapters 4 and 5 showing that many teenagers cannot make themselves understood easily when speaking to strangers, very few could use money and many would not be able to say their name and address if lost, then one can see why for the majority their lives are so restricted, when compared to ordinary teenagers.

Surprisingly, perhaps, our teenagers belong to clubs as much as ordinary teenagers, but the difference being that our teenagers are likely to only be mixing with other handicapped teenagers, so it will not be helping their social development greatly.

Our teenagers are much less likely to go to parties and discos that are real teenage parties, rather than adult or adult supervised parties. Indeed, our young people are still spending almost all their leisure time in the company of their families. This gives them little opportunity to develop friendships with others of their own age, nor to mix with and learn from other teenagers.

As in all the other aspects of the teenagers progress we looked at, there were fairly wide variations in these social contact, social independence and leisure areas also.

On all three aspects of social development, there were no signficant differences between the boys and the girls, and in fact, in the social independence area the boys were slightly in the lead.

This is the only area of development where there is no overall improvement with age, the older teenagers are having just as restricted a social life as the younger ones.

As one might expect, the more able the teenagers on everyday living scores, school achievements and communication the better their scores on these social competence measures.

The greater the teenagers' score on social independence, the wider his range of leisure pursuits and social contacts.

The teenagers' scores for difficult behaviour showed no effect on these social competence measures, suggesting that the type of behaviours shown are not socially disruptive.

Parents ratings of the effect that the teenager had had on the family and brother and sisters were not related to these social competence measures but the rating of family attitude was. The more positive the family were in their attitudes towards the child, the higher the social competence scores of the teenager. This may suggest that families feel more positive about more socially competent and active teenagers, or that positive families have encouraged more progress in the child.

The teenagers position in the family is having the same small effect on progress as in all the earlier measures of developmental progress, except on the measure of social independence. Only and youngest teenagers seem to be benefitting to some extent from more adult time and attention in terms of their range of leisure activities and social contacts. Teenagers in the middle of the family were ahead of the only and eldest children on the measure of social independence.

The advantages of higher social class of the family can be seen reflected in the teenagers scores for range of leisure pursuits and social contacts.

CHAPTER 7

GENERAL BEHAVIOUR AND PERSONALITY

The many physical changes which occur during adolescence are accompanied by changes in behaviour and feelings. It is the period during which many of the changes concerned with the transition from childhood to adult status occur and many cultures have special rituals to signify this change. The main differences between the pre and post adolescent state are concerned with the taking on of adult roles in life with the responsibilities of making a living and fulfilling one's role in sexual and family life. Different cultures cope with this transition in many difference ways - from highly structured procedures where the change in role is very clearly defined to societies such as ours, where the transition to adult life may take a very long time and where the 'rules' are rather vague. This uncertainty is frequently reflected within the family by the absence of specific expectations of particular types of behaviour of young people of various ages. The problem is clearly more complicated where the adolescents are handicapped.

The greater physical size and strength and mental ability is often associated with more assertive behaviour and the many other changes which anticipate the adult role in life.

During their progress through childhood our expectation of our childrens' behaviour changes - we expect them to abandon their more infantile behaviours and to accept more responsibility for themselves and others and to behave in ways which are more socially acceptable. Sensitivity to the feelings of others and the ability to co-operate in existing social structures become more and more necessary.

In designing the section of the questionnaire that asked about general behaviour, we selected questions that would give us an idea of the young person's usual behaviour each day in order to build up a picture of what they were like to live with. We focused on actual behaviour so that any comments we make about personality are inferences based on the overall picture of each teenager that emerged from the questionnaire and interview.

The first question we asked was "Is your child generally a happy person?" and 89 out of 90 parents answered "Yes" with no hesitation. We felt this to be an important response as it suggested that the teenagers were cheerful people, nice to have around on the whole. Certainly this was the feeling conveyed throughout almost every questionnaire - that the young person did provoke feelings of warmth and a positive response in the family. They were much loved within their families despite, in some cases, being quite physically dependent and in the majority of cases needing a lot of supervision as we have seen in the preceeding chapters.

These young people with Down's syndrome seemed to be particularly sensitive to the feelings of others. This acute awareness of the emotional atmosphere was been remarked upon by many parents - in spite of the fact that the question was not specifically asked. Some of the comments made were as follows.

"He is upset by arguments or raised voices."

"If either parent is a little depressed he will try and cheer them up."

"He has a good sense of humour and will make people laugh."

"He is affected by contentious atmospheres even when the argument is trivial."

"..... gives a lot of affection."

"when on youth club holidays, she has an amazing ability to cheer up another teenager who is moody. We often send her off to "sort someone out".

There is a big difference between the percentages of Down's syndrome adolescents who live at home with their families and those with autism. In our study 89% lived with families and the other studies report very similar figures (78% Carr,1985; 85% Gath, 1985) while 34% of adolescents with autism lived with their families (Wing, L, personal communication).

It seems very likely that the most important difference between these two groups which determines the much higher rate of acceptability of those with Down's syndrome is their emotional sensitivity and warmth - characteristics which are lacking in those with autism.

People who suffer from childhood autism never develop real personal relationships because they are unable to empathise with the feelings of others, do not understand the values of social conduct, cannot communicate properly and will often express their feelings or behave in an embarrassing way because they have no understanding of the social context in which they find themselves.

The ability of people to communicate with one another at an emotional level, almost regardless of the difference in intelligence, is something which virtually all human beings value very highly. Perhaps people with Down's syndrome are helpfully drawing attention to this aspect of human life.

As far as personality is concerned, the conventional stereotype of the person with Down's syndrome as being placid, outgoing, compliant and affectionate (Gibbs and Thorpe 1983) was confirmed as you can see from the data summarised in Table 7.1. According to our parents over two thirds of our teenagers were not often difficult or naughty, too excitable and lively nor, conversely, too inactive.

The majority were able to occupy themselves quite happily without bothering parents constantly - even though their activities were rather passive and solitary such as watching TV and colouring or playing alone in their rooms.

You can also see from the answers to the first five questions, that not only are the majority happy, cheerful and generally well-behaved young people, but that those who are difficult improve with age. Only two older girls are difficult and six older boys.

The fact that around a third can be difficult or naughty sometimes, seems fairly normal, especially as these behaviours were usually related to being cross when not able to get their own way or frustrated when trying to make themselves understood.

From our data, we would not describe the majority of the teenagers as passive. This description only applied to some of the more dependent teenagers, with poor communication and poorly developed skills; handicaps which would not allow them to actively engage in leisure pastimes or social activities. Some of these passive teenagers had abnormally low scores for difficult behaviours; they did very little at all. However, for the sample as a whole, the less able teenagers tended to be the more difficult.

The one teenager who was not generally happy according to her mother was described as a "worry". She was an only child and her mother became a widow when she was very young. She was very lively, wearing her mother out because she was on the go all the time and because she could also be very difficult and self-willed. She had a number of difficult behaviours including frequently hiding things both at home and at school, picking her nails, masturbating and dribbling. She was described as living in a fantasy world for a large proportion of her leisure time, with numerous fantasy friends. This mother seemed rather isolated and very anxious about the burden of coping with her daughter, particularly in the long term.

In discussing the types of difficult behaviour that the families reported, it is important to bear in mind that these behaviours were not a frequent or serious problem for the majority. The majority were not seen as generally difficult to manage nor miserable to be with, both factors presumably contributing to the warmth families expressed and the low demand for services, as you will see in Chapter 10.

Difficult Behaviour

Overactivity
Overactivity in children is a complex subject and is sometimes more related to the level of tolerance of the parents than to observable behaviour. One third of the boys of all ages were described as often too lively and excitable while 17% of the younger and only 5% of the older girls were thought to be too active. These active teenagers were described as "on the go all the time, loud and noisy and easily overstimulated", and in some cases were clearly very demanding. The description "passive" certainly did not apply to over a quarter of the sample.

Coping with change
While three-quarters of the teenagers were able to cope with change without any difficulty, parents of the remaining quarter reported that they did find their teenager upset by change. (Curiously none of the younger boys seemed to have any difficulty in this respect).

Some of the teenagers simply showed signs of distress and took a while to settle in new situations. Others clearly felt more secure in a familiar environment and routine and insisted on daily routines being carried out even at home or they became upset.

Provocative Behaviours
Behaviours such as stubborness, swearing and temper tantrums could be interpreted as being deliberately annoying. As you can see from Table 7.1 about a third of the sample had temper tantrums and about half of the teenagers swore at times though few parents were distressed by this. Deliberately annoying behaviours which could be interpreted as reactions to frustration or as attention-seeking in nature are therefore, quite common. Such behaviour becomes more and more unacceptable with increasing age and interferes with the more normal aspects of social development. Temper tantrums and other forms of attention seeking behaviour are usually very successfully dealt with by completely ignoring them while at the same time rewarding socially acceptable behaviour.

Other types of annoying behaviour were ignoring parents instructions and repeating requests back rather than complying.

TABLE 7.1 - GENERAL BEHAVIOUR

QUESTION		YES		NO		SOME TIMES	
		-14	+14	-14	+14	-14	+14
Often too lively/excitable	G	17	5	66	95	17	-
	B	32	27	64	68	4	5
Inactive/needs prompting to be busy	G	11	9	78	64	11	27
	B	18	9	68	64	14	27
Can be difficult naughty	G	33	9	56	73	11	18
	B	18	23	68	59	14	18
Any strange or unusual behaviour	G	33	9	67	91		
	B	29	18	71	82		
Cries a lot	G		9	94	86	6	5
	B	4		93	95	3	5
Has difficulty coping with change	G	17	23	72	77	11	
	B		13	100	73		14
Situations often frighten child	G	56	50	39	50	5	
	B	36	50	53	50	11	
Deliberately annoys parents	G	33	14	61	86	6	
	B	46	14	50	86	4	
Problems over going to bed	G	39	4	61	91		5
	B	25	23	71	73	4	4
Problems during the night	G	33	9	56	91	11	
	B	32	9	68	86		5

Bed-time Problems

Of the under 14 year olds 39% of the females and 25% of males had troubles about going to bed but this fell to 4% for the over 14 year old females although there was not much change in the males. The problems consisted of slowness in getting undressed and other delaying tactics such as going up and down stairs at bed time and unnecessary requests. About a third of the under 14's remained unsettled during the night; the commonest problem being wandering into the parents room and often getting into their beds. Many parents gave in for the sake of a peaceful night and allowed the child to stay in bed. In spite of this, the behaviour was less frequent in the over 14's (9%).

Other difficulties consisted of wandering around the house, numerous trips to the toilet or for drinks of water. These activities were often done very loudly and lights were often left on and/or doors left open disturbing the rest of the household. Some would play quietly with their toys, often in the early hours of the morning, without disturbing the rest of the house.

Distressing behaviours

TABLE 7.2 - FREQUENCY OF DISTRESSING HABITS

QUESTION		YES		NO		SOME TIMES	
		-14	+14	-14	+14	-14	+14
Nailbiting	G	17	32	83	58		9
	B	18	27	82	73		
Spitting	G		5	100	95		
	B	14		86	100		
Hair-pulling	G	6		94	100		
	B	11		89	100		
Hurting self/ others	G	22	14	78	86		
	B	22	5	78	95		
Breaking things	G	6		89	95		5
	B	7	9	93	86		5
Temper tantrums	G	33	27	56	68	11	5
	B	29	23	68	68	3	9
Other difficult behaviours	G	17	9	83	91		
	B	29	32	68	68	3	
Swears	G	44	59	56	41		
	B	50	55	50	45		
Parents distressed by swearing	G			100	91		9
	B	3	14	93	82	4	4

Table 7.2 illustrates the frequency of distressing habits which parents found objectionable. As you can see, the majority of the teenagers do not have distressing behaviours at all. Although swearing was common - ranging between 44-59%, the vast majority of parents were not distressed by it. The fact that there was somewhat more of this behaviour in the over-fourteens suggests that there were factors outside the home that reinforced this behaviour. Most distressing habits were less frequent in the older age group. In the over 14 age group spitting almost disappeared as did hair pulling, breaking things and temper tantrums. However, nail biting remained common and showed an increase with age.

Other difficult behaviours reported included dribbling, emptying drawers and cupboards, scratching themselves and throwing food. Very few of these were considered to be serious by parents and were much less frequent in the older age group. Some teenagers had habits which led to hurting themselves or others occasionally. One in five of the younger children, but only four older children.

Fears and Phobias
Inappropriate fearful reactions to everyday situations were relatively common. About one fifth of the sample were reported to be frightened by sudden loud noises, thunderstorms and strange dogs. A small percentage (13%) were frightened when in the presence of people arguing and some teenagers were still afraid of the dark. There was a fairly wide range of fearful reactions but they were individually uncommon.

On average about half of the children had fearful reactions to common situations.

The treatment of fears and phobias is generally very successful and it is advisable to obtain the help of a skilled behaviour therapist to treat them since, in addition to the associated anxiety, they may place unnecessary restrictions on the life of the individual and their family.

None of the children showed behaviours which could be interpreted as being bizarre or as manifestations of mental illness of any kind (in the Isle of Wight study the prevalence of such behaviours in teenagers was 5.4% (Rutter,1971).

From the psychiatric point of view adolescence is significant in several different ways, not the least of which that it is often a time that signs of serious mental illness may appear, that anti-social problems become serious, and that difficult and self-centred behaviour may reach levels where it has disruptive effects upon family life. It is interesting, therefore, that we found no one with serious mental disorder in our sample. It seems that this lack of serious psychiatric disorder in adolescence continues to adult life since disorders such as schizophrenia and disorders of mood are exceptionally rare in adults with Down's syndrome.

Other Studies
It is difficult to compare our results with those of the various other studies which have examined behaviour in people's Down's syndrome because the definitions of behaviour vary so widely. Often any unusual or deviant behaviour is seen as psychiatric disorder without taking the nature or the severity of the behaviour into account or, more importantly, the type of child and the situation in which this behaviour occurs. In ordinary children, it is difficult to decide whether particular behaviours are psychotic, part of a behavioural disorder, more specifically situational in nature, or part of the range of normal behaviour for a particular age group. It is very much more difficult to do so when the child is handicapped since the real significance of particular behaviours is even more difficult to assess. We have tried to divide difficult behaviours into "basically ordinary" and "bizarre or unusual" behaviours because these ordinary and bad behaviours are seen in virtually all children at some time or other, whereas the "bizarre/unusual" behaviours tend to have a different kind of significance being more likely to be associated with serious long term difficulties. We defined "ordinary behaviours" as those behaviours which, while they could be described as annoying, provocative or attention seeking were basically understandable although mostly seen in children of a very much younger age. Because of these difficulties reported rates of psychiatric "behaviour disorder" in children with severe mental handicap vary in different studies between 75% (Kamimer et al, 1984), 50% (Rutter, 1979), 25% (Groden et al, 1982) and 20% (Stein and Susser, 1975). In Down's syndrome, Menolascino (1967) found 37% of thirteen year olds with "psychiatric disorder".

The most detailed study of behaviour difficulties in children with Down's syndrome is that of Gath & Gumley (1986). In their study they were able to compare the parents perceptions of their children's behaviour with the data obtained from rating scales completed by both parents and teachers.

Parents thought that 15% of the teenagers with Down's syndrome had significant behaviour problems, yet 38% would have been so classified on the basis of the rating scales used. Comparable figures for their comparison group of equally retarded but non-Down's syndrome children were 25% and 49% respectively. These figures suggest that children with Down's syndrome show significantly less difficult behaviour than other equally retarded children. They also suggest that parents do not regard some behaviours as particularly difficult, although they are judged as such on the rating scales used by professionals.

Gath & Gumley found that parents considered overactive and bizarre behaviours as the most distressing and difficult to cope with. The parents were not likely to see the more dependent children as a problem unless accompanied by difficult behaviour. In their study, mothers judged as having a psychiatric problem themselves were more likely to perceive their handicapped child as having significant behaviour problems. Severity of behaviour problems in the child was not related to family size, to the age or educational achievements of the mother, to the physical health of either parent, to relationships with members of the extended family or to social class .

They did find significantly more disturbed behaviour in children in care but we did not - (see Chapter 10). They report fewest behaviour problems in the children of widowed or divorced mothers, with a significant difference between them and the children in homes where the marriage was rated as moderate or poor.

Considering the type of behaviours shown Gath and Gumley (1986) described 9% of those with Down's syndrome as having "severe Psychiatric disorder" 11% with "conduct disorder", 13% as "hyperactive" and 40% as having "severe and distressing problems". We would not describe any of our sample as psychiatrically disturbed.

Carr and Hewett (1982) found that three-quarters of their sample at the age of 16½ were said to be "easy to get along with" and the remaining twelve "fairly easy". Four-fifths were described as able to occupy themselves "most of the time". These findings are very similar to our own.

Shepperdson (1984) in the South Wales Study found that 13% of mothers saw the child as "difficult" and 15% as "difficult to some extent".

Some parent's compared their teenager with Down's syndrome very favourably with ordinary teenagers, describing them as "more gentle", "lacking aggression", "having an open, friendly manner" and "without any prejudices".

She emphasises that the range of behaviour reported was wide and eight had surprised their mothers by not conforming to the placid stereotype, by being extremely active.

She felt that 40% of her group had some negative behaviours such as extreme wilfulness, being difficult to discipline or control, or being excessively demanding or disruptive.

Violent or aggressive behaviour was not common. Eight teenagers had temper-tantrums if thwarted and 5 could be destructive. Four had shown a marked deterioration in behaviour and ability over the years.

Shepperdson described 18% of the parents as strict and parents felt that strictness paid off. Certainly, her data would confirm this. Families who were rated as strict when seen in 1972 now had teenagers with no behaviour problems. Carr also reports that firm discipline reduces problems in her sample.

Oster and van den Temper (1975) found that most parents in their large study agreed that the most encouraging fact about their children was that they were happy, friendly and usually good humoured.

Factors which may be related to difficult behaviour

The teenagers were each given a score for difficult behaviour based on their parents' answers. The more difficult their behaviour, the higher their score as points were given according to the number and severity of difficult behaviours exhibited.

The maximum score which could be obtained was 36 and the mean score for the whole sample was 8.0. As we have already described in this chapter, the young people do not exhibit a great deal of difficult behaviour and a score of 8.0 would be reflected by the occasional outburst of temper, stubbornness, occasional defiance and bed-time delaying tactics. All pretty normal for teenagers! In other words, those young people who had very low scores were unusually passive and unresponsive.

There was no significant sex difference as the mean score for the girls was 7.62 and for the boys 8.48.

There was an important improvement with age as you can see in Table 7.3. The mean score for the younger group of 9.22 and for the older group it is 6.93. This is encouraging and shows that behaviour is improving and tends to be less difficult in the later teens. This difference is approaching statistical significance.

TABLE 7.3 - MEAN SCORES FOR DIFFICULT BEHAVIOUR FOR YOUNGER AND OLDER GROUPS

Age Group	N	Difficult Behaviour Score (DBS) Mean DBS	SD DBS
Under 14	46	9.22	5.76
Over 14	44	6.93	4.31

(p= 0.08 approaching sig.)

Table 7.4 shows the mean scores for difficult behaviour according to the young person's position in the family.

TABLE 7.4 - THE EFFECT OF FAMILY POSITION ON DIFFICULT BEHAVIOUR SCORES

Family Position	N	Mean DBS
Only	8	7.13
Eldest	21	7.81
Middle	10	10.30
Youngest	43	8.26
Total	82	8.28

(ANOVA p = 0.48 ns)

As you can see, only children have an advantage again - they show the least difficult behaviour with eldest children next then youngest. Once again those young people in the middle of families do not seem to fare as well.

TABLE 7.5 - THE EFFECT OF SOCIO-ECONOMIC STATUS ON DIFFICULT BEHAVIOUR

Socio-economic Group	N	Mean DBS
I & II	25	9.08
IIIn & IIIm	35	8.09
IV & V	23	8.04
Total	83	8.37

(ANOVA p = 0.32 ns)

Differences in difficult behaviour between groups based on social class (Table 7.5) can be seen to be small.

While the tendency is for those from the more advantaged homes to show more difficult behaviour, this difference is too small to suggest any meaningful effects.

Ill health in the young person does seem to be important and related to difficult behaviour as you can see in Table 7.6.

TABLE 7.6 - THE RELATIONSHIP BETWEEN ILLHEALTH AND DIFFICULT BEHAVIOUR

Health Problem	N	Mean DBS
None	30	6.03
Minor	26	9.04
Moderate	20	8.60
Severe	14	10.07
Total	90	8.10

(p = 0.07 approaching significance)

Clearly, the healthiest group show the least difficult behaviour - rather less than average for the sample as a whole. Those with mild and moderate health problems are a little above the mean. The group of fourteen teenagers with the severe health problems also score rather higher than average on difficult behaviour.

TABLE 7.7 - THE DIFFERENCE IN MEAN DIFFICULT BEHAVIOUR SCORES (DBS) BETWEEN SCHOOLS

School	N	Mean DBS
1	11	8.09
2	11	9.91
3	13	5.85
4	13	6.92
5	13	10.85

(ANOVA p = 0.04 significant difference)

As discussed earlier, in Chapter 4, the school environment does seem to be significantly related to difficult behaviour. Some schools have children showing significantly less difficult behaviour than others as you can see from Table 7.7

It would seem that the expectations of staff, their techniques for dealing with difficult behaviour and for encouraging competent and socially acceptable behaviour do produce measurable differences in the behaviour of their pupils.

The influence of difficult behaviour on the teenagers other achievements

Table 7.8 shows the correlations between the score obtained by each teenager on difficult behaviour and their scores for the skills we measured.

TABLE 7.8 - CORRELATIONS BETWEEN THE MEASURE OF DIFFICULT BEHAVIOUR AND OTHER SKILLS

	Everyday Living Skill	School Achievement	Communi-cation	Leisure Activities	Social Contact	Social Indepen-dence
Difficult Behaviour	-0.43 p 0.01 sig	-0.14 p=0.08 ns	-0.26 p 0.01 sig	-0.09 ns	-0.09 ns	-0.19 ns

You can see from the table that poor behaviour is associated with some achievement areas and not others. Teenagers with more difficult behaviour tend to have significantly poorer achievements in everyday living skills, although difficult behaviour seems to be unrelated differences in to school achievement.

There is a significant negative correlation with communication skills, suggesting that some difficult behaviour could be the result of frustrations when unable to communicate. Parents often gave examples of this type of frustration. (see Chapter 4, Table 4.10)

Most surprisingly, the difficult behaviour is apparently having no effect on social competence. This may be because, in fact, even teenagers with moderate scores on difficult behaviour were not persistently difficult to a degree that was regularly anti-social.

Difficult behaviour and family attitudes

Finally we looked for any inter-relationship between difficult behaviour and the way families felt about their young person.

As you can see from Table 6.9 difficult behaviour has no influence on family attitudes.

TABLE 7.9 - CORRELATIONS BETWEEN MEASURES OF FAMILY EFFECTS AND DIFFICULT BEHAVIOUR

	Family Attitude	Effect on Family	Effect on Siblings
General Behaviour	0.08 ns	0.12 ns	-0.01 ns

(These measures of the families attitudes are explained more fully in Chapter 9)

Summary

Our main findings are that teenagers with Down's syndrome tend not to have serious behaviour problems and violence and aggression was very uncommon compared with other teenagers whether mentally handicapped or not. It therefore seems that children with Down's syndrome are comparatively well behaved compared with other adolescents. The problems mentioned by parents were generally not severe and are mostly of the type that could be considered as either part of ordinary development although occurring at later ages, or as reactions to the frustrations of being unable to communicate adequately.

None of the teenagers showed severe anti-social activities such as serious violence, drug taking or truly destructive behaviour. While 22% of males and females under fourteen might hurt themselves or others, this figure fell to 14% for females and 5% for males over the age of fourteen - but this was not serious in degree in any of the families.

We did not find any behaviours which could be interpreted as being associated with mental illness. However, problems such as swearing and annoying behaviours were fairly persistent. There were many kinds of phobias and about one half of the children were affected by them.

There was an association between communication and behaviour in that poor expressive language was likely to be associated with disturbed behaviour. This association has been described elsewhere (Gath, 1985) and is probably due to the frustration involved in being unable to express oneself.

In general, difficult behaviour was not a serious problem and seemed to be much less problematic than in non-handicapped teenagers.

One important characteristic of the group was their sensitivity to the feelings of others. This emotional perceptivity was appreciated by the families and was seen as a postive contribution to family life and may be partly responsible for the large number of teenagers who are kept with their families. They were seen as generally happy, cheerful and warm individuals.

CHAPTER 8

PHYSICAL DEVELOPMENT AND HEALTH

All chromosome disorders produce a wide variety of physical defects but in general these tend to be milder in Trisomy 21 than in the other disorders. As has been pointed out in the introductory chapter, the most serious physical problems are present at birth and by the time early teenage is reached many of them have been resolved one way or another; modern medicine and surgery having made an enormous impact on congenital cardiac, gastro-intestinal and other problems.

In the pre-antibiotic era the morbidity and mortality in Down's syndrome was very high indeed, with the average life expectancy in institutions averaging about 19 years of age. Since the discovery of antibiotics the life expectancy of those who have overcome the medical problems of early life has changed dramatically. With proper diagnosis and treatment even the most serious infections can be successfully treated and life expectancy is now commonly 35 years of age or more. Half of all those who reach 10 years of age, will reach 60 and some will live to 70 or older (Collacott, 1987).

The effect of particular diseases, general health and motor abilities on general development and learning in children has been the subject of many studies. Chronic and recurrent illnesses which keep children away from school and reduce their interaction with people outside their immediate families interfere with their general development and learning progress and may also affect their behaviour.

We looked at the rate of growth, type of physique, motor skills, vision, hearing and some aspects of health and how ill health may have affected other aspects of their development.

Growth

It has been maintained that children with Down's syndrome are usually shorter and smaller than ordinary children (Chumlea et al,1981). Our data confirms that these teenagers tend to be shorter and that they reach physical maturity earlier. The normal range for the menarche (the appearance of the first menstrual period) in this country is between 10 and 16½ years with a mean at 13 years. In our sample the range was also from 10 to 16 years but the mean was between 11 and 12 years ie 1-1½ years earlier than the standard figure.

These results differ from some other studies such as Bellone (1980) who found that periods started one year later.

However, Pueschel (1985) found that the mean bone age in a sample of males with Down's syndrome was slightly more than the chronological age and it may be that in some ways people with Down's syndrome do reach their own level of maturity and stop growing earlier than others.

Physique

People with Down's syndrome people have been traditionally described as all being short and mostly fat or at least stockily built.

Our data (Table 8.I) tend to support this general view although there are some important differences. The decision as to whether someone is short or not or is too heavy for their height tends to be somewhat arbitrary. Analysing our data on height with a cut off point for shortness where the individual is shorter than the shortest 10% of the population of the same age, 66% of the sample could be defined as being short for their age.

TABLE 8.1 - AVERAGE HEIGHT & WEIGHT

	Girls -14	Boys -14	Girls +14	Boys +14
Average weight	6st 3½lb	6st	7st 4½lb	8st 3lb
Average height	4ft 6ins	4ft 6ins	4ft 8ins	5ft 0½ins

Using similar reasoning for weight we selected the cut off point of the 80th percentile - ie, if the individual weighed as much as those in the top twenty per cent of the population of the same age they were considered to be overweight.

Using these criteria 22% of the sample were overweight. 42% of the sample were below the third percentile for both weight and height, ie., they were small but not overweight.

It can therefore be seen that about 20% were not short, about 22% were short and overweight and 42% short but not overweight. This shows that there is a fairly wide variation in body types in Down's syndrome and that it is not possible to make simple generalisations about their physique.

Since hypothyroidism is associated with people who are overweight and both overweight and deficient thyroid function is common in Down's syndrome it must not be assumed that overweight with or without sluggish behaviour is purely the result of Down's syndrome. It is advisable to have a high index of suspicion and to consider that all people with Down's syndrome may be hypothyroid. There is, indeed, a very good case to be made for having the thyroid function in all people with Down's syndrome tested regularly.

Problems of overweight

On the basis of parental opinion, we divided the teenagers into two groups, overweight and not overweight.

5I% of the girls were considered to be overweight by their parents and 36% of the boys. The problem showed a slight increase with age as 37% of the younger children but 49% of the older ones were considered overweight. In Shepperdson's (I984) study 46% of parents considered their teenager to be overweight.

Being overweight had no influence whatsoever on any other area of the teenagers development that we looked at. The majority (78%) of the parents of those considered overweight were concerned about it and wanted advice on how to control the weight problem.

Motor Skills

Good control of one's body is an integral part of human development and physical ability is obviously important in terms of its relevance to self-help skills, mobility, weight control, vocational abilities, and the enjoyment of leisure pursuits.

It is part of common observation that motor development in people with Down's syndrome lags behind that of a comparable group of the same age (Rarick et al 1976). Cratty (1974) using a test battery of his own devising pointed out special difficulties in balance and visual tracking in people with Down's syndrome. Cullen et al (1981) and Reed et al (1980) have pointed out that good muscle tone and no (or minor) congenitial heart problems were positively related to scores on tests of social maturity and also to potential response in the ability to use professional help. Good muscle tone was associated with better language acquisition, motor and social development and mental functioning.

Henderson et al (1981) found that seven to fifteen year olds with Down's syndrome were less active, slower in performing tasks and had poorer balance than normal children while Kay and Bankhead (1983) found that seventeen year olds had the same reaction time as other retarded children. (A few of our mothers reported that their children had very delayed reaction times to painful stimuli).

Our data (Table 8.2) shows that the type of skills important in every day life such as walking, climbing stairs, riding a tricycle, kicking, throwing and catching a ball, are achieved by more than 90% of our children and it would appear that their development and every day lives were not much hampered by problems in motor development. However, about 40% could not swim without aids. This seems a pity since it is an excellent form of exercise and it is quite likely that the use of skilled teachers of swimming for the handicapped could improve this figure a great deal.

Only about 30% could ride a bicycle without stabilizers (as opposed to a tricycle which could be ridden by approximately 83%) suggesting that balance was a real problem.

Of course, physical activity may be restricted by other factors such as heart disease, hearing and visual defects and clearly children will not reach their full physical potential until these are properly diagnosed and treated.

Although there are many special schemes for improving physical performance, in practice almost any muscular activity is beneficial so that whatever activity the individual finds enjoyable should be very positively encouraged. Competitive sports are becoming increasingly popular and many Down's syndrome people particularly enjoy dancing which is a form of exercise which tends to benefit neuromuscular and perceptual conditions.

The general flaccidity of muscle tone and looseness of ligaments and joints in Down's syndrome is associated with extreme physical flexibility, so much so that they have been called "double-jointed" (although there is no such thing). This flexibility makes it easier for them to sit on their feet in a way that would be awkward or painful for others and to contort their bodies in unusual ways.

TABLE 8.2 - PHYSICAL - MOTOR SKILLS DEVELOPMENT

QUESTION		YES		NO		PARTLY	
		-14	+14	-14	+14	-14	+14
Can do unaided:							
Walk	G	94	100	6			
	B	100	100				
Climb stairs (1 foot each step)	G	89	91	6	9	5	
	B	89	95	7	5	4	
Climb stairs (2 feet each step)	G	94	95	6	5		
	B	100	100				
Jump (both feet together	G	89	91	6	9	5	
	B	96	91	4	9		
Hop on one foot	G	72	91	22	9	6	
	B	86	82	14	14		4
Thread large beads	G	89	95	11	5		
	B	86	91	14	4		5
Swim without aids	G	33	59	61	41	6	
	B	57	64	32	32	11	4
Ride a bike	G	22	23	61	77	17	
	B	36	50	53	50	11	
Ride a Trike	G	78	95	22	5		
	B	86	73	14	27		
Kick a ball	G	100	95		5		
	B	100	100				
Catch a ball	G	89	86	5	14	6	
	B	86	91	11	5	3	4
Throw a ball	G	100	95				5
	B	96	100	4			

Some people have suggested that most forms of exercise should be avoided because the lax ligaments in the two top vertebrae at the base of the skull may be more susceptible to the phenomenon known as atlanto- occipital dislocation. This is almost certainly very bad advice. Apart from the fact that there has been only one reported case of this injury in the United Kingdom, the best way of protecting against it is to have good strong muscles in the neck and skull area and the best way of achieving this is by frequent suitable exercise. Only those activities which might directly injure this area, such as diving, should be avoided.

Common Illnesses

In the past infectious diseases were the main cause of illness in Down's syndrome. It is now known that people with Down's syndrome have various defects in the defence mechanism against invading organisms. We asked parents how often their teenagers suffered from common infectious illness.

Only 18% of the girls and 6% of the boys were on regular medication. As you can see in Table 8.3 coughs and colds are the most common problem affecting half the sample "sometimes" and around a quarter "often".

TABLE 8.3 - COMMON ILLNESSES
FREQUENCY

		OFTEN		SOME TIMES		RARE		NEVER	
		-14	+14	-14	+14	-14	+14	-14	+14
Coughs	G	17	18	55	50		14	28	18
	B	21	27	43	41	4	18	32	14
Colds	G	28	18	61	55		9	11	18
	B	39	36	50	37	4	18	7	9
Sore Throats	G	6	13	33	41	6	23	55	23
	B	14	5	21	32	4	9	61	54
Ear infections	G	11	9	17	13		23	72	55
	B	7	5	22	23	7	4	64	68
Skin infections	G	22	18	11	5		9	67	68
	B	14	27	14	14		9	72	50
Stomach upsets	G	17	18	44	14		27	39	41
	B	11	5	25	18	7	18	57	59

More than half the sample never or only "rarely" had sore throats, ear infections, skin infections or stomach upsets.

Skin infections were a frequent problem for about a quarter of the teenagers. Sore throats and ear infections were rarely a frequent problem, but did affect over a quarter of the teenagers sometimes.

It seems that upper respiratory tract infections are the most common illness, followed by skin infections, but none of these illnesses were a frequent or serious problem for most of our group.

This finding that health is generally good as the children get older is confirmed by Carr & Hewett (1982). Forty of their 43 teenagers were described as having had good health in the last 5 years. Only one had had an accident, three had developed deafness and three had become epileptic. Over a quarter had had a significant illness.

In Shepperdson's (1984) study 72% of parents felt that their teenagers were in good health and 53% said their health had improved as they got older. Only two reported poor health.

Vision

For the younger children 56% of the girls and 43% of the boys have a visual defect. For the older children the figures are 64% for the girls and 53% for the boys. All these children wear glasses to correct their visions except two.

Only 6 of the total of 46 children wearing glasses were said to dislike them. These figures are considerably higher than those found in the general population (approximately 3%) and are supported by others studies. Shepperdson (1984) found that 58% of her group had some vision problems, two severe. Pesch et al (1978) found a large number of visual defects in a sample of 41 people with Down's syndrome. Most had long sight but they also found short sight, astigmatism, strabismus and many other visual disorders. This high incidence of visual disorders is important, not only for the obvious reason that most of the defects are correctable but also because visual disorders are especially likely to delay all aspects of their early development.

TABLE 8.4 - AGE AT WHICH VISUAL DEFECT DETECTED

Age defect identified	0 - 2		3 - 5		6 - 8		9 - 11		12 and over		not known	
	-14	+14	-14	+14	-14	+14	-14	+14	-14	+14	-14	+14
Girls	20	-	10	14	30	14	20	29	-	22	20	21
Boys	25	17	25	33	25	8	25	34	-	8	-	-

Table 8.4 shows the age at which these visual defects were first identified. The ages at which they were first detected seems rather high and it is quite likely that more detailed examination may have revealed them at a younger age. Regular testing of vision from babyhood is important for all with Down's syndrome.

Hearing

In our sample 10% of girls and 19% of boys had had their hearing tested in the previous two years but 80% of the parents could not remember the last time their child's hearing had been tested. Only 3 girls and 8 boys were reported as having hearing defects and 3 of these wore hearing aids. This is a remarkably small number of hearing difficulties for people with Down's syndrome; Dahle and McCollister (1986) found that 77% if their sample had some hearing loss. The commonest problems were excessive wax in the ears, (a fairly easy problem to deal with) but more serious disorders, including glue-ear, were very common.

This suggests that our figures are an under-estimate of the real incidence of hearing problems and that most of these teenagers have not been adequately assessed.

Hearing is the most important of the senses concerned with learning, communication and social interaction and it should be tested regularly and every effort made to improve it as much as possible.

Thyroid Dysfunction

It has been known for many years that defective thyroid function is commoner in people with Down's syndrome. (see Kinnell et al 1987 for a recent review). We found two youngsters with defective thyroid function in our sample; a smaller number than we had expected, but at least 20% of the total group were not sure that their child had ever been tested. Defective thyroid function may develop at any age and with the increased likelihood of this occurring in Down's syndrome it is important to test for this if there is the slightest suspicion that it may be present.

Missing the diagnosis of hypothyroidism is an extremely serious matter since not only is the diagnosis comparatively easy to make but the treatment is extremely effective and without side effects. If the diagnosis is made early the effects of poor thyroid function can be completely compensated for by administering Thyroxin in tablet form. This substance is identical to that produced by the thyroid gland and used correctly has no side effects. It is therefore one of the best forms of treatment in all medicine and it is obviously important not to miss the opportunity to produce the change from an overweight physically and mentally sluggish individual to someone who is brighter and more active.

Epilepsy

In the past it was generally believed that epilepsy was rare in Down's syndrome (Kirman 1951) but Veall (1974) and others have suggested that the incidence increases with age. We found two people with epilepsy in our sample: this agrees closely with Veall's figures of 1.9% for people under 20 years of age, and is higher than that found in the general population of the same age. Shepperdson (1984) found three boys on medication for epilepsy in her sample of 53 teenagers . The possible presence of epilepsy must therefore be investigated and treated as in other situations.

Cardiac Disorders

32% of our sample had heart defects with identical figures for boys and girls. The incidence of cardiac disorders in Down's syndrome is particularly high but modern cardiology has changed the outlook for the majority of people in a most encouraging manner. Surgery, if required, will usually be carried out in early childhood.

The range and severity of health problems

On the basis of the information on health provided by parents each teenager was given a rating for health problems which put him or her into one of four groups.

The kind of persistent health problems rated were those felt to be likely to have an effect on the young persons' development. The results are given in Table 8.5 for the whole sample.

TABLE 8.5 - THE EXTENT OF SIGNIFICANT HEALTH PROBLEMS

Health Problem	N (%)
None	30 (33)
Minor	26 (29)
Moderate	20 (22)
Severe	14 (16)
Total	90(100)

One third of the teenagers had no particular persistent health problems. Just under a third had minor health problems which left just over one third with moderate or severe health problems.

Put another way, only one out of every three teenagers could be said to be free of any persistent health problems. Of the other two out of three, one is likely to have some minor problems and the third moderate to severe health problems.

There was no difference between boys and girls and both groups had the same distribution of health problems. The same was true for the younger and older age groups, suggesting that the distribution for persistent health problems is not changing. It is getting neither worse nor better as the young people get older.

The effect of ill health on the teenagers development

Table 8.6 shows the influence of persistent ill health on the range of school achievement areas that we measured.

TABLE 8.6 - THE INFLUENCE OF ILL HEALTH ON SCHOOL ACHIEVEMENTS

Health Problems	Reading	Writing	Arithmetic	Money	General Knowledge	Total ScAch Score
None	12.10	7.9	7.50	6.80	23.3	57.60
Mild	14.38	7.96	9.09	9.57	25.46	66.48
Moderate	12.25	6.50	7.07	7.85	20.20	53.88
Severe	9.00	6.21	6.96	9.07	17.93	49.18
	p=0.4	p=0.64	p=0.44	p=0.52	p=0.21	p=0.46
Mean Total Group	12/31	7.34	7.78	8.19	22.40	58.03

You can see that there are very few differences amongst the first three groups, but those teenagers with severe problems are rather behind their peers in most areas. They are well below the mean for the sample in all areas except money skills (in which all were poor).

Ill health has had less effect on social competencies as you can see from Table 8.7.

TABLE 8.7 - THE INFLUENCE OF ILL HEALTH ON SOCIAL COMPETENCE

Health Problem	Leisure	Social Contact	Social Independence
None	17.82	11.67	2.87
Mild	18.77	9.23	2.42
Moderate	16.92	9.20	2.95
Severe	18.28	10.00	1.93
	p=0.67	p=0.19	p=0.69
Mean Total	17.97	10.16	2.61

It is only in the area of social independence that ill health has impaired performance.

TABLE 8.8 - THE INFLUENCE OF ILLHEALTH ON COMMUNICATION

Health Problem	N	Mean Communication Score
None	30	13.90
Minor	26	12.58
Moderate	20	11.05
Severe	14	8.64
Total	90	12.06

(ANOVA p 0.01 sig)

There seems to be a clear effect of poor health on communication skills. This is clearly demonstrated by the data set out in Table 8.8. There is also more difficult behaviour in those with severe health problems (see Chapter 7, Table 7.6).

The effect of social class

As you can see in Table 8.9, there is a signficant difference in the health ratings in the different social class groups.

TABLE 8.9 - THE EFFECT OF SOCIAL CLASS ON ILLNESS RATINGS

Social Class	N	Mean Score
I & II	25	0.88
IIIn & IIIm	35	1.20
IV & V	23	1.56

(p = .07)

The advantages of more material resources, perhaps more warmth in the home, more money for good, clothes, and medicine were showing benefits in better health.

Summary

Our sample of teenagers showed a wide variation of body-types but they are mostly shorter than normal children. Females had their first period about I-1½ years earlier than non-Down's girls. Both boys and girls were poor on tasks which required good muscular co-ordination.

Once people with Down's syndrome reach their teens many will have overcome the many serious medical problems of early life to a considerable extent. They are generally a healthy group but they do tend to have a high incidence of problems concerned with vision, hearing and infections. They are more likely to have thyroid disorders and, to a lesser extent, epilepsy. An association was found between the severity of on-going ill health and communication skills as well as social independence and difficult behaviour.

Teenagers rated as having severe and persistent illness problems were delayed in all areas of achievement. This data emphasises the importance of good health and the contribution it can make to the teenager's progress and their quality of life.

It is important therefore to detect impairments in vision, hearing and thyroid function as soon as they occur. Treatment or prescription of suitable aids is likely to produce considerable improvement in function. Good general health care and prevention and treatment of infection is also important. Ideally each person with Down's syndrome should have a full health check at periodic intervals of about 3 years.

Useful review chapters on hearing (Davies), vision (Millis) and motor skill development (Henderson) are to be found in Lane & Stratford (1985) Current Approaches to Down's syndrome.

CHAPTER 9

SEXUAL DEVELOPMENT AND BEHAVIOUR

Until very recently little thought was given to the sexual development and behaviour of handicapped people living in the community, and even less to those who live in more or less closed institutions. With the current emphasis on more integration with the community at large and, in the case of Down's syndrome, tremendous improvement in health and longevity, these matters are becoming increasingly important.

As in so many other areas, literature on the subject is somewhat sparse and contradictory. There have been some recent studies examining sexual development.

Physical development and fertility

Males

Pueschel et al (1985) measured the genitalia and three hormones (testosterone, luteinizing hormone and follicle stimulating hormone) in 46 young males with Down's syndrome. They found no real differences in the measurements between the subjects examined and standard values used to judge such tests. They did find, however, that axillary and facial hair was thin and sparse in the Down's syndrome group although there was no difference in pubic hair. A number of questions concerning sperm production, and sexual desire remain unanswered.

Although there is no recorded case of a male with Down's syndrome having fathered a child (the one possible exception to this finding was reported to be a Mosaic Down's syndrome) there seems to be no reason, on the evidence so far, why they should not be able to do so.

In our sample 59% of the older boys were shaving but none of the younger ones. Of those who were shaving, 23% started at 14, 32% at 15 and the remaining 4% at 16. Half of these lads could shave without any help at all, a quarter were being shaved by parents and the other quarter were able to manage with some help.

TABLE 9.1 - DEVELOPMENT OF FACIAL HAIR IN BOYS

Age started to shave	14	15	16	None Shaving
Under 14				100
Over 14	23	32	4	41

TABLE 9.2 - INDEPENDENCE IN SHAVING

	YES	NO	WITH HELP
Can cope with shaving unaided over 14	54	23	23

Females

Some of the data concerning sexual development in females is somewhat contradictory. Figures from the USA show that the average age of onset of menstruation was found to be 12 years and 6 months, compared to 12 years and one month in non-handicapped females (Scola and Pueschel, 1985).

We found that the mean age for the first period was between 11 and 12 years of age. This compares with a mean of 13 years for England as a whole. There is an association between the onset of menstruation and the cessation of growth and it may be that this is part of the reason why Down's syndrome females tend to be shorter.

TABLE 9.3 - AGE OF ONSET OF MENSTRUATION

Age started periods	10	11	12	13	14	15	16	Not Known	Not Started
Under 14		28	11						61
Over 14	5	27	23	14	9	5	4	4	9

TABLE 9.4 - ABILITY TO COPE WITH MENSTRUATION

		YES	NO	WITH HELP	MOSTLY	SOMETIMES
Can cope with	-14	29	43	14		14
periods unaided	+14	55	25	5	15	

Table 9.4 shows that 25% of the over 14 year olds and nearly half the under 14 year olds could not cope with their periods by themselves. This can occasionally be a serious problem where some of the girls are unable to manage sanitary towels at all nor the associated problem of good cleaniness.

Sometimes these cannot be dealt with satisfactorily even after prolonged attempts at training and there are instances where the only way of coping with these problems is to suppress menstruation altogether. However, three-quarters of the older girls were well on the way to coping satisfactorily with their own care.

Occasionally the problems of menstruation are aggravated by a deterioration in mood and behaviour during the 4 to 5 premenstrual days and sometimes during the period as well. Medical advice should be sought in these cases since it is often possible to alleviate these symptoms.

Pregnancy

Since most Down's syndrome females do not have the opportunity of being allowed to become pregnant the nature of their fertility is difficult to assess. Tricomi, Velenti & Hall (1964) found that 38% showed an ovulatory pattern, 31% may have actually ovulated and 30% showed no evidence of ovulation.

These figures are low and suggest that Down's syndrome females are subfertile.

Bovicelli et al (1982) reported on 30 pregnancies (including one of his own patients) in twenty five mothers with Down's syndrome (four having had two pregnancies). Of these pregnancies ten resulted in children with Down's syndrome, seventeen without and three resulted in abortions. Theoretically half of the offspring of a mother with Down's syndrome should have this condition. The smaller ratio reported (10:17) may be due to the greater likelihood of foetuses with Down's syndrome being aborted - this is a tendency in all pregnances with Down's syndrome foetuses (Boue 1981). Of the 17 children who did not have Down's syndrome 6 were abnormal mentally and/or physically; this may be partly explained by the high incidence of incest and the difficulties surrounding birth due to problems such as small and misshapen pelvic bones. The overall figure of 19 abnormal outcomes from 30 pregnancies demonstrates the very high risk of problems when Down's syndrome females become pregnant.

Sexual behaviour

Of the boys in our study a quarter of those under the age of 14 years were interested in girls while there were twice as many over the age of 14 years. Of the girls one half of those both below and above 14 years were interested in boys (see Table (9.3). This interest is mostly passive and no parent described any attempt at real heterosexual behaviour.

The incidence of masturbation which was twice as common in boys as in girls was not clearly connected with the likelihood of the youngster being interested in the opposite sex.

TABLE 9.5 THE TEENAGERS SEXUAL BEHAVIOUR

QUESTION		YES		NO		SOME TIMES		DON'T KNOW	
		-14	+14	-14	+14	-14	+14	-14	+14
Interested in opposite sex	G	44	50	56	50				
	B	25	41	75	55		4		
Interested in sexual activity	G	11	9	89	86				5
	B	7	5	93	95				
Any understanding sex/babies	G		18	11	68	Partly 89	9		5
	B	4	14	82	68	14	18		
Any sex education at home	G	5	14	89	68	6	18		
	B	14	4	86	91		5		
Any sex education at school	G		23	89	50	5	9	6	18
	B	7	23	64	73			29	4

TABLE 9.6 - SEXUAL BEHAVIOUR

QUESTION		YES		NO		SOME TIMES		DON'T KNOW	
		-14	+14	-14	+14	-14	+14	-14	+14
Child masturbates	G	22	18	61	73	11	6	6	
	B	25	50	39	36	36	14		
Parents distressed by masturbation	G	5	5	89	95	6			
	B	3	18	86	73	11	9		
Masturbates when tired	G	50	33	50	67				
	B	41	14	59	86				
Masturbates when bored	G	33	50	67	50				
	B	59	43	41	57				
Other	G	17	50	83	50				
	B	12	21	88	79				

In general very few parents were concerned about the sexual behaviour of their children.

Shepherdson (1984) found that most parents were ready to accept that their teenagers would experience sexual urges and were ready to be understanding but the sexuality of boys was seen to be more threatening than that of the girls because they felt they were more likely to show unacceptable behaviour in public and might, therefore, get into trouble with the police or neighbours.

At least half of the boys had begun to show an interest in girls but only two mothers were worried about this. Three mothers were worried about masturbation because they thought that their sons might do this in public. Several mothers felt that their daughters would welcome the attentions of men and would be especially vulnerable but there was little fear about pregnancy. Mothers dealt with these problems by avoiding explicit TV programmes and by verbal correction and advice - boys were told not to touch or kiss girls and girls were told not to indulge in provocative behaviour.

Sex education was limited to warnings rather than explanations. Only six (11%) felt that their teenagers had any notion of sexual intercourse, twenty-seven (51%) of pregnancy and twenty-one (40%) of the process of giving birth to a child.

Over one third felt that no explanation was actually possible or even necessary since the opportunities to become involved in troublesome sexual behaviour would not be present. Most of the parents who agreed with the desirability of sex education preferred it to be given at school rather than at home.

Parents' Knowledge and Concerns

Table 9.7 shows that very few parents had received any information or advice about their children's sexual development and only one quarter had any ideas about the likely fertility of their child.

TABLE 9.7 - PARENTS KNOWLEDGE AND CONCERNS

QUESTION		YES		NO		SOME TIMES	
		-14	+14	-14	+14	-14	+14
Any advice on birth control	G	17	14	83	86		
	B	7		93	100		
Any advice on sex. development	G	6	5	94	95		
	B	7	9	93	91		
Aware of child's likely fertility	G	22	23	78	77		
	B	21	18	79	82		
Does child's sex development worry you	G	67	41	28	50	5	9
	B	25	32	75	68		

Parents of the girls were more concerned about their daughter's development than parents of boys, largely because of the fears of pregnancy and exploitation. However, the lack of concern of parents of the boys probably also reflected the tendency for their sons to show little interest However, 32% of parents had worries concerning the sexual behaviour of their male children (see Table 9.7). These worries seemed mainly concerned with the future since there were no reports of troublesome sexual behaviour at the present time.

Where advice is available it tends to deal with the following types of problems:

1. Resisting unwanted advances. Most people feel that even if this is taught well, females particularly, remain susceptible and the problem of adequate supervision remains.

2. Relationships. Teaching people the idea that sex is only part of a widely based relationship which includes other factors such as respect for one's partner, sensitivity to their needs and the ability to support each other is difficult to do. Mattinson (1975) has described mutually helpful and supportive behaviour between mentally handicapped couples.

3. The difference between public and private behaviour. The majority of parents, while objecting to any form of sexual behaviour in 131 public directed their teenagers to masturbate in private. Some authors feel that the pleasure and relief from tension that this gives is important and that sufficient effort should be put into teaching teenagers to obtain sexual relief in private (Craft 1986).

Contraception

Very few of the parents in our sample had obtained advice on birth control (Table 9.7) and this may reflect the difficulties in using some of the more common forms such as the contraceptive pill, the diaphragm and the sheath. The contraceptive pill can be given under supervision but in practice this tends to be difficult and other methods such as hormonic injections and surgical sterilisation have been used. There are a number of females who have had hysterectomies as a way of dealing with the problems of contraception, inability to manage menstruation and related problems with a single permanent solution.

It is important to emphasise that the parents must take advice from more than one source and that they should insist on the method that will be most practical for everyone and most free of anxieties.

The problem of contraception for both males and females with Down's syndrome is complex, not only because of the different ethical and religious issues involved but also because of the uncertain state of the law as well as the technical problems associated with different methods of contraception.

Suitable sex education in which the nature of personal relationships, sensitivity to the feelings and needs of others, and the meaning of contraception is essential where a sexual relationship is likely and the use of suitably qualified councellors and printed material from organisations such as the Health Education Council or Family Planning Association is usually necessary.

All handicapped people must be protected from exploitation by others, whether sexually, physically or in other ways. They should be helped to understand the dangers of inappropriate sexual behaviour in public and the problem of sexual relationships in general.

There would seem to be no purpose in becoming involved in the problems of contraception unless there is a very real likelihood of the person concerned becoming involved in a sexual relationship or in the small group of people who may engage in promiscuous behaviour; the dangers of emotional and physical harm as well as venereal disease in this group needs to be stressed.

For people who have difficulties with number work, the significance of times and dates and compliance in the use of most form of contraception will be a serious problem. For such people the contraceptive pill and barrier methods of contraception such as the condom or the diaphragm are not realistic methods.

In practice, where compliance cannot be relied on, the intra uterine device (IUD) or surgical methods such as vasectomy or tubal ligation or injectable hormones are the only dependable means of contraception.

Clearly, each situation must be considered on its own merits and impartial advice must be sought. It is equaly important to ensure that suitable follow-up and supervision continues as long as any non-surgical method is used.

It is usually necessary to reiterate the fact that, with the exception of the condom, no method of contraception protects against any of the venereal diseases.

The evidence suggests that people with Down's syndrome are not highly motivated to seek sexual relationships but where this is a possibility it is important that the implications are all carefully considered. The high incidence of handicapped babies born to mother's with Down's syndrome is discussed at the beginning of this Chapter.

Summary

For most teenagers and families, their sexual development and behaviour is not a problem.

However, very few parents had received any advice and were concerned about the future sexual needs of their offspring. Very few teenagers had had any education either - clearly an area which should concern schools.

Some understanding about pregnancy and sexual behaviour at an appropriate level is important, not only to ensure that the young persons can manage their own behaviour appropriately, but also to enable them to avoid exploitation. Some understanding of their own development is important if the onset of menstruation and wet dreams are not to be frightening experiences.

Education should therefore include information on their developing bodies, sexual behaviour and contraception if appropriate. It should also include teaching on resisting unwanted advances; an individual's personal worth; friendships and relationships and the differences between public and private behaviour.

The reader is recommended to consult the publications of Ann Craft on sex education and counselling for mentally handicapped people (Craft, 1983, 1986).

CHAPTER 10

FAMILY LIFE

Assessing the nature of family life, let alone the effects of a handicapped child upon it, is extremely difficult. Measuring the way people respond to various events in their lives, such as the birth of a handicapped child is exceptionally complicated and analysing the nature of a presumed stress is difficult for many reasons. Stresses vary in severity from time to time and may be composed of factors which work in different ways, some of which may actually be beneficial in the long run.

It has been repeatedly observed that the "same" stress may have a very different effect upon different people, depending on their situation and their perception of the stresses. For example, a serious life-event such as divorce may have an extremely traumatic effect on one case, whereas it may be responded to with relief in another. In addition to these difficulties there are complicated discrepancies between the way we perceive things at any given moment and the actual situation. For example, a woman may complain that her husband almost never washes the dishes while objective observations may reveal a very different picture.

These factors, among others, help to account for the fact that so much research into family processes is unsatisfactory and difficult to interpret. In spite of all these problems, it does seem, judging from other studies and the way they have been followed up that investigating attitudes on their own may be helpful in understanding how people cope with their problems. We therefore asked parents in our sample open-ended questions about how they saw the effects of having a Down's syndrome child in the family.

On the basis of parents' answers to the questionnaire as a whole and to the questions specifically about the effects of the child on the family, each family was given three ratings. One is a measure of the families attitude towards the teenager. The second reflects the families assessment of the effects the young person with Down's syndrome has had on their family life in general. The third score reflects the families assessment of the effect on brothers and sisters (siblings) in particular.

For each of these three family measures we have used a rating scale. The scores from 1 to 5 reflect whether the family were generally rather positive or negative in their expressed feelings and attitudes towards the young person.

A score of 1 means the family were very positive about the teenager and a score of 5 means they were very negative.

The families attitudes towards their teenagers
The families attitude towards the teenager was rated on the basis on their generally positive or negative attitudes conveyed during the interviews and in the answers on the questionnaire.

Overall, the families feelings about their teenagers were not affected by the sex of the young person or their age. The mean rating for the girls was 2.35 and for the boys 2.65. The mean rating for the under 14's was 2.43 and for the over 14's 2.63. All these mean scores are towards the positive end of the rating scale (3 being the mean point).

TABLE 10.1 - THE EFFECT OF FAMILY POSITION ON THE FAMILIES ATTITUDE TOWARDS THE CHILD

Family Position	N	Mean Score	SD	Range
Only	8	1.87	0.99	1.0-3.0
Eldest	19	2.47	0.69	2.0-4.0
Middle	10	3.20	0.79	2.0-4.0
Youngest	39	2.56	0.91	1.0-3.0
	76	2.55	0.90	1.0-4.0

(The lower the score, the more positive the family attitude
p = 0.03 sig)

The families attitudes were significantly affected by the position of the child in the family. As you can see from Table 10.1 it is the pattern we've seen before in earlier chapters, the only children evoke the most positive attitudes and the middle children are once again at a disadvantage.

TABLE 10.2 - CORRELATIONS BETWEEN THE MEASURE OF FAMILY ATTITUDE AND THE TEENAGERS ACHIEVEMENTS

	Self Help	School Achieve-ments	Communi-cation	Leisure Activities	Social Contact	Social Indepen-dence
Family Attitude	-0.28 p 0.01 sig	-0.32 p 0.01 sig	-0.32 p=0.002 sig	-0.24 p=0.01 sig	-0.34 p=0.001 sig	-0.25 p=0.01

As you can see from Table 10.2, the measure of family attitude shows a significant negative correlation with all the measures of the teenager's achievements. This means that the higher the teenagers achievements in all these areas, the more positive the family tend to be. Unfortunately we can only speculate on the possible causal connections. It may be that families who are generally more positive encourage their young people to achieve more. Alternatively, it could be that the families feel more positive because their children have achieved more.

Only a longitudinal study which could measure these things over time for the same families can resolve this ambiguity.

The effect the teenagers have had on the families

About 30% of the parents said that the child had not had any especially good or bad effects on the family but had been much like any other child. 48% made positive remarks about the effects of the child, such as; "prevents us from stagnating; brings out the best in the other children; has made us a very close family; she's lovable and kept us young; has made me and the children better people".

37% pointed out negative effects such as; "Causes lack of sleep; very hard work; plays us off against each other and we have rows; our choices are reduced because of her; has caused a lot of stress; causes anxiety as she is apt to walk off".

A third of the parents of the older children made both positive and negative remarks such as; "We have always been tied down but she has always generated happiness", "feel isolated sometimes but she is a ray of sunshine". Less than one in five of the parents only mentioned negative effects.

When we gave a rating to the responses of the families to the questions on the effect they felt that their young person had had for good or bad in the family, we found no differences according to the sex or age of the teenager.

The mean rating for the boys was 3.11 and for the girls 3.26. The mean rating for the under 14's was 3.07 and for the over 14's 3.29. You will notice that these ratings are a little more negative than those for the families attitude towards the child. They mostly were warm and positive about the young person themselves, but could see realistically that there had been both positive and negative effects on the family as a whole and that there were some costs to bringing up a special child.

The figures in Table 10.3 show that for this measure, family position has little significance. The mean scores do vary in the now familiar way, but the differences are too small to be of any real relevance here.

TABLE 10.3 - THE EFFECT OF FAMILY POSITION ON RATINGS OF THE EFFECT ON THE FAMILY

Family Position	Mean Rating	SD	Range
Only	2.75	1.03	1.0-4.0
Eldest	3.16	0.60	2.0-4.0
Middle	3.50	0.97	2.0-5.0
Youngest	3.26	0.99	1.0-5.0

However, if you look at the range of ratings used, none of the families of only or eldest children felt the effects had been so bad as to be given a rating of 5. If you look back at Table 10.1 no family at all was sufficiently negative in their attitudes towards their child to be rated as 5.

Table 10.4 shows the correlations between the rating for effect on the family and the other achievement scores. It again shows a small but significant negative correlation across all the achievement scores leaving us with the same interpretation problem as before.

TABLE 10.4 - CORRELATIONS BETWEEN THE RATINGS OF EFFECT ON THE FAMILY AND THE TEENAGERS ACHIEVEMENTS

	ELS	School Achievements	Communication	Leisure Activities	Social Contact	Social Independence
Effect on family	-0.22 p=0.02 sig	-0.24 p=0.01 sig	-0.27 p 0.01 sig	-0.13 ns	-0.25 p=0.01 sig	-0.11 ns

Other Studies

There have been many studies designed to evaluate the effect of children on family life but few have specifically examined the effect of the teenage Down's syndrome child. Billy Shepperdson (1984) found that 24% of mothers responded positively to the birth of their child and resumed normal life very quickly, often within days. She also found that when she compared the attitudes of the mothers at birth with their attitudes now that they had had teenage children, the number of mothers who responded positively increased. 51% found it easier to cope with teenagers while 26% found that problems have increased in that age group. She remarks that the negative responses recorded in her study were probably due to a clustering of several factors which combined to cause problems, eg higher social class, poor response by other family members, lack of home support, abnormalities in work situation or difficulties in coping with work, birth of an unwanted (not simply unplanned) handicapped child.

Carr and Hewett in their study published in 1982 found no evidence of major disadvantages either on the family or particularly on the brothers and sisters.

Gath and Gumley (1986) found that mothers who thought that their Down's syndrome child had serious behaviour problems were more likely to have psychiatric disorders themselves. It is difficult to interpret this finding since the nature of this interaction cannot be unravelled on this data alone.

The effect of the teenagers on their brothers and sisters

When we asked what effect the teenager had had on his brothers and sisters 21% of mothers with female Down's syndrome children and 30% of mothers with male Down's syndrome children said that there were only good effects. For example, they made remarks such as:

1. "It increased their sense of responsibility."

2. "They have learned tolerance of the mentally handicapped."

3. "They have been made more aware of those less fortunate."

4. "They feel very protective towards their brothers and sisters."

About of 26% of mothers felt that there had been some adverse effects.

Remarks such as the following were made:

1. "The other children may have felt pushed out."

2. "They may have had lack of attention and time."

3. "They may have felt frustrated."

4. "The child gets on everyone's nerves because of being so demanding."

5. "Being protective towards her causes disputes with other children."

6. "Resentful of the extra attention he receives.'

7. "Sometimes embarrassed when friends come around, very jealous"

40% of mothers with female and 35% of mothers with male Down's children felt that there had been no special effect upon the siblings at all and the remaining 10% or so felt that there had been both positive and negative effects.

About two-thirds of mothers saw the effect of having a Down's child as generally positive or neutral.

When we gave each family a rating based on their answer the families views of the effect the teenager has had on his or her brothers and sisters show no significant difference according to sex or age. The mean rating for the boys is 3.00 and for the girls is 2.96. The mean rating for the younger teenagers is 3.00 and for the older ones is 2.97.

TABLE 10.5 - THE EFFECT OF FAMILY POSITION ON EFFECT OF SIBLINGS

Family Position	Mean Rating	SD	Range
Eldest	3.11	0.76	2 - 4
Middle	3.33	0.87	2 - 4
Youngest	2.87	1.02	1 - 5

As you can see from Table 10.5 the rating of the effect that the young person had on brothers and sisters is not affected significantly by whether they are the eldest, middle or youngest.

There is a tendency for the teenager to be seen to have had the least negative effects on brothers or sisters when he or she is the youngest in the family.

Table 10.6 shows the correlations between the ratings for the effect of siblings and achievement scores. As you can see, there are no significant correlations with everyday living skills and school achievement - so here the abilities of the young person are irrelevant. Families do not consider that the brighter, more able children have had any more or less negative effects on their brothers and sisters than the less able teenagers, which seems a surprising result.

TABLE 10.6 - CORRELATIONS BETWEEN THE RATINGS OF EFFECT ON SIBLINGS AND THE TEENAGERS ACHIEVEMENTS

	ELS	School Achievements	Communication	Leisure Activities	Social Contact	Social Independence
Effect on siblings	-0.13 ns	-0.17 ns	-0.30 p 0.01 sig	-0.18 p=0.06 ns	-0.28 p 0.01 sig	-0.01 ns

Similarly, there is no correlation with scores on the range of leisure activities of social independence. There are, however, correlations with scores on communication and social contact.

Teenagers with better communication skills and more social contacts were rated as having a less negative effect on brothers and sisters.

Carr & Hewett (1982) had asked mothers what effect they thought their handicapped teenager had had on brothers and sisters. In their group 17% thought that there had been negative effects, 30% thought there had been positive effects and 35% thought there had been both good and bad effects.

In this study, the authors had a comparison group of normal teenagers. They found more siblings with difficult or disturbed behaviour in the families without a handicapped member on objective rating scales. The mothers of ordinary teenagers only, reported that they had worries about their other children in 46% of the families, compared to 22% in the families with a Down's syndrome teenager.

In Shepperdson's study she also reports that parents perceived both positive and negative effects on brothers and sisters. In childhood, about one third of the siblings had shown minor forms of irritation, dissatisfaction, embarrassment or jealousy. Only three had suffered more severe problems and most were enthusiastic and loving brothers and sisters. In the teenage years, the nuisance value had disappeared as behaviour improved but parents noted that the relationship could not be one of real companionship.

Gath and Gumley (1986), like the other authors, found no evidence that brothers and sisters had any greater incidence of behaviour problems than in any ordinary family.

In their group, disturbed behaviour in siblings was more likely to be found in families where the child with Down's syndrome was also showing difficult behaviour. In turn, this pattern in the children was associated with marital discord or disturbance in a parent, so that in fact all the children may be reacting to stresses in the family.

These figures do not therefore vary a great deal but suggest that siblings, on balance, do not suffer to any great extent from being a Down's syndrome brother or sister.

In spite of this a considerable proportion of mothers did feel that they should have given their other children more time and more attention. These data also tend to support the view that brothers and sisters take their lead on how to respond to their brother or sister with Down's syndrome from their parents. This work is consistent with other work in this field (Rutter 1979), that where parents cope with the everyday problems of life in a positive way the children in the family tend to do the same.

The effect of social class

As you can see in Table 10.7 we did not find that the social class of the family had any significant effect on their attitudes towards their teenager or their perceptions concerning their effects on the family.

TABLE 10.7 - THE RELATIONSHIP BETWEEN SOCIAL CLASS AND THE RATINGS OF FAMILY ATTITUDES AND EFFECTS (Mean scores)

Social Class	Family attitude	Effect on family	Effect on siblings
I & II	2.4	2.9	3.05
III & IIIm	2.5	3.3	3.00
IV & V	2.7	3.3	2.90

(no significant differences)

Social restriction on family life

When we asked all families if they felt that their child had restricted their family life over 60% said no. Of those who said yes, 37% of the sample were quite specific saying that they would have liked a greater choice of leisure and holidays.

There were also statements such as; "Our world totally revolves around her", This statement, while it shows important mutual benefits in the family, could also be seen to be unhelpful in terms of developing independence in the child.

Typical remarks were as follows:

1. "Where he goes we go."

2. "He does not like shopping - gets bored very quickly."

3. "Has prevented us from going to museums etc."

4. "Holidays must be self-catering."

5. "Country walks are a drag, not a pleasure."

6. "Museums, concerts, exhibitions are very difficult."

7. "Can't relax on the beach."

8. "We would have to look after him all the time on holiday."

9. "Being older parents we are quite happy with our way of life."

10. "We do everything together."

It is clear that families who were interested in active sports such as cycling, walking, skiing etc had to either give up these activities or arrange for alternative occupation for their children. This was also true for activities such as visiting museums and exhibitions, but two-thirds of the mothers stated that their social and leisure activities had not been affected in any substantial way.

Those parents who expressed more negative attitudes seemed to miss activities of the type that their children did not like. Families that were able to adjust to this - either by doing other things or by arranging for a separate occupation - responded with an all-round positive view in respect of most factors of the family life. It seems that the families that functioned well had children who were reasonably well behaved, particularly in public, and were integrated into family activities to a very large extent. This combined with higher expectations appears to reduce many adverse affects upon the family.

Other findings
Shepperdson (1984) found that 32% of parents said that having a Down's syndrome child made them have a more restricted social life. This figure had gone up to 47% nine years later when her group were teenagers. She suggests that this is because a mother with a small child expects to be restricted while one with a child in its teens does not as in fact the families were still going out as often as when visited earlier. Carr & Hewett (1982) reported that, in their study, families with a teenager with Down's syndrome did not differ from those with ordinary teenagers in the frequency of outings or holidays that they had with their children.

Teenagers in care
At the time of the survey, we found eleven teenagers in care. Of these eleven six had been in care since birth and another five children had gone into care during their childhood.

Table 10.8 and Table 10.9 shows the mean scores of the eleven teenagers in care, for all the measures of development that we have. These children are in children's homes or hostels - we have not included those who are in substitute families.

TABLE 10.8 - MEAN SCORES FOR ACHIEVEMENTS OF YOUNG PEOPLE IN CARE

Group	N	ELS	SAS	Leisure Activities	Social Contact	Social Independence
Care since birth	6	98.7	47	15.5	12.2	2.3
Care later	5	105.0	49.9	19.0	12.0	2.8
Care total	11	101.5	48.3	17.1	12.1	2.5
Means - full sample	90	92.1	58.03	18.0	10.1	2.6

You can see that as a group these teenagers are not significantly different from the whole sample. They have a slightly higher mean score for Everyday Living Skills and for social contact. They are a little behind as a group on School Achievement. Their mean scores for communication skill, leisure activities and social independence are very close to the means for the whole sample. Interestingly, they have much less difficult behaviour.

TABLE 10.9 - MEAN SCORES FOR COMMUNICATION, ILL HEALTH AND DIFFICULT BEHAVIOUR FOR CHILDREN IN CARE

Group	N	Communication	Illness	Difficult Behaviour
Care since birth	6	10.5	1.3	6.0
Care later	5	13.6	1.0	2.6
Care total	11	11.9	1.2	4.5
Means - Full Sample	90	12.1	1.2	8.1

On the whole you can see that the five who went into care later are doing rather better on all the measures than those who have been in care since birth.

Of the five who went into care later, 2 were from homes unsettled by divorce, I had a widowed parent, one still had both parents at home and for the fifth child no information on parents was available. The practical stresses of trying to cope as a single parent seemed to be the major factor in determining the need for care, not severity of handicap as reported by Carr & Hewett (1982) in their sample.

It would seem that it is not the young person's dependency needs at home or behaviour that make life difficult to manage, but the practical difficulties arising from their social dependency, ie needing to be met from the bus each day and supervised at meals etc. One parent, probably needing to work, will find it very difficult to cope.

Support for families

Over 60% of our families had one or more relatives living near by, but only a third of the families said that they received practical help from relatives. A third of the families received support from friends, so that those with relatives near were not necessarily any better off in terms of help with the teenager than those without.

Less than one in five of the teenagers had ever had a holiday or short-term care. Two children went to hospital units once a year to give families a break, but four out of five families received no respite care of any kind.

Despite this, the families were not anxious to demand services. Just over half the families did not require anymore services at present, nor did they feel that they had needed more help in the past.

With regard to their need for services in the future, 80% of the parents of the girls felt that they would need more support but only half of the parents of the boys.

These figures highlight the extent to which these families have adjusted their lives to accommodate to the demands of their handicapped teenager. The majority were coping with out major perceived stresses and did not feel the need for more support.

In the interview situation we often had to press families to think about the future and what they would like for their teenager. Often they wanted them to stay at home, and would only make choices regarding preferred residential provision when we asked where they would want them to live if they could not longer cope.

At the present time, 17% of the parents said that they would like more leisure facilities, 13% would like short-term care, 9% would like a holiday play-scheme or holiday care, 6% more speech therapy and 4% better educational provision and more opportunity for integration. Only 2% wanted a home-help or more financial help.

When asked about what extra services they would have liked in the past, 17% felt that they would have liked more contact with professionals, 16% more accessible information, 13% more short term care, 9% more extended holiday playschemes and leisure facilities, 7% more speech therapy, 6% wanted babysitters, and 4% a home help. Only 3% wished that they had had more contact with other parents or more financial help. Only two families would have liked more local social support, one family - more family support, one would have liked a more positive attitude from their GP and one would have liked Portage intervention.

(Although only one family mentioned their GP in this section of the questions, many more commented negatively about the early days and the unhelpful and inaccurate prognosis they had been given).

When we asked parents about the future we received an even shorter list of requirements. 14% would like more leisure facilities for young adults, 9% would like better work facilities, 8% better educational provision, 4% short-term care, 3% more opportunity for integration, more financial help and more contact with professionals. Only 2% wanted more speech therapy and holiday care and one family wanted a home help. Only one family asked for better acceptance by the community.

Other Studies
Gath & Gumley (1986) report that 14% of their group received regular support from a grandmother and 33% from neighbours and friends. Hostels for short-term care were used by 44% of the group and 13% used hospitals for a holiday break. Half their parents were appreciative of relief care, commenting that it was a good experience for the child as well as a useful break for them but 30% of parents were clearly dissatisfied with services.

In Shepperdson's (1984) group, 57% had some form of short term care and seven of the less able had regular care several times a year.

The Future

Occupation
When we asked parents what sort of future work they would like for their son or daughter when they left school, 48% preferred real work of some kind rather than a training centre. Some of these parents suggested particular types of work, 8 chose outdoor or agricultural work, 3 - work with children, 2 - cooking, 1 - craftwork and 1 - housework. Most parents felt that they wanted work for their young person that was interesting not monotonous or boring, kept them alert and active, used their abilities to the full but was not too difficult and did not exploit them.

Since we asked what they wanted, not what they did not want, we got mainly positive answers. Six families stated that they did not want an Adult Training Centre place. One parent stated "I think that the training centre is slave labour and turns them into cabbages".

Nine (10%) of the parents stated that they wanted a place in the Training Centre. In several cases these were parents of more severely handicapped young people who feared that they might not be acceptable in the Training Centre, and so have no day care at all after leaving school.

Leaving home
When we asked parents when they would like their child to leave home, we found that more than half did not want them to leave. 26% of the families firmly replied never, a further 16% stated "only when we can no longer cope" and 10% "only if he wants to leave", making 42% in all. We only found 17 (19%) of families who saw leaving home as a positive move to encourage and would state an age. Twelve (13%) of these families thought 19-20 years would be about right and a further 5 (6%) thought somewhere between 20-25 years. Of the remaining families 6% felt that they did not know and 12% did not answer the question.

When we asked parents what kind of place they would like their son or daughter to live in when they do leave home, we only obtained answers from 42(47%). Of these, half (22) favoured a small group home near the family, with friends, 14 preferred a hostel with a warden, 7 preferred a sheltered village community and 3 felt their son or daughter would cope in a flat. Four families were not sure which type of provision they preferred. One family hoped their son would marry and live independently, and 8 wanted somewhere with a family atmosphere.

It was clear that for many parents the future care of their young person was a major worry. For most it was a rather distant concern but for some a major one.

One mother stated "My greatest worry at present is that I have no idea what would happen to him if I died tomorrow as I know of no suitable place for him".

This last phrase summed up the feeling of many parents. Their desire to keep their son or daughter at home did not necessarily reflect over-protectiveness. In the answers to what they wanted for their son or daughter in terms of work, many mentioned independence, a chance to use their abilities, to continue education and to mix with normal people. Rather, their desire to keep their young person at home reflected the view that suitable alternative homes were simply not available. They did not feel at all confident that the quality of provision that they knew about was acceptable.

One mother felt so strongly that her son would not be well cared for that she told us she would contemplate giving him an overdose if she knew she was dying herself and "take him with her".

Another stated " I would rather he died that go into an institution".

Other Studies
Shepperdson(1984) reports that the parents in her group had much the same feelings about the future as ours.

Few parents felt positive about residential care except of the sheltered village community type. Only 46% of the parents expected their teenagers to eventually need residential care and 36% thought that the family would cope. Indeed, she found that two sisters had already assumed the responsibility and a third intended to. A further 19% did not know what would happen and 3 or 4 hoped that their young person would eventually be able to live in the community with minimal supervision.

Summary
The most striking finding was that, in spite of the fact that the youngsters were clearly in need of a great deal of attention and that their degree of independence was much less than that of non-Down's syndrome children of the same age their parents did not perceive these factors in a particularly negative light. In fact the majority of parents made very specific statements about the positive effects of having a Down's child in the family. Some compared their Down's children favourably with others as being more gentle, less aggressive and more friendly.

This generally positive attitude, against a background of poor achievement and some social restriction is reflected by the large number of families (83%) who still have their child living with them, and the 42% who wish them to remain with them for the forseeable future into adult life.

It seems very likely that the good emotional contact that families are able to achieve with their Down's syndrome children is an important factor in seeing them in this positive light.

This is in contrast to the situation in families who have children with a similar degree of handicap but with the autistic syndrome. These adolescents, who are unaware of the feelings of others, do not take part in the emotional and social life of the family and demands for long term care and other services tend to be considerably greater in these families. This matter is also discussed in Chapter 7. As a group the families functioned well and there was no suggestion that the child was being blamed or held responsible for any specific family difficulties. The overall negative effect on family life of children of this type is small.

In our sample 11% were in care, usually because a single parent could not manage the practical supervision required. This percentage is small and does not affect the conclusions to any great extent.

It seems that the objective problem is in some way less important than the manner in which it is perceived and the way in which it is dealt with. Most parents would like their children to be more independent and better behaved and would have welcomed help to achieve these aims. It therefore seems likely that they would be able to take advantage of guidance in learning techniques in management and in particular help in the skills of behaviour modification since these techniques have had such a dramatic effect in improving the self-help skills and social functioning of people with handicaps.

Most families were living their lives with the minimum of practical support at home or breaks for the teenager provided by short-term care but most were not anxious for more services.

For the future, the majority of parents wanted their young person to have an interesting daily occupation, within his capabilities and for them to lead as full a life as possible.

However, half the parents did not want their son or daughter to leave home at all unless it became a necessity when their own health failed. This did not seem to us to reflect overprotection but rather a lack of confidence in the suitability and quality of available provision.

CHAPTER II

CONCLUSIONS AND RECOMMENDATIONS

In our introduction, we stated that our aim in conducting this survey was to try and find out what daily life was actually like for the teenager with Down's syndrome and for their families.

In this concluding chapter, we will try to draw together a picture of the life of a typical teenager as portrayed by our results and to draw out the implications for services.

However, before we do this it is important to emphasise that there is a wide range of ability and that, in fact, life for each of these teenagers is unique to them and their family.

To illustrate the wide range of abilities, we have put together some typical case histories of young people with different levels of abilities and family situations. These are composite and therefore do not represent specific people, but they are based on the actual young people we studied.

Alan is an example of one of the more able, Kevin and Sharon are in the middle range of abilities and Mary is rather less able. We ranked all the teenagers on their ability in everyday living and school achievement skills. Alan is based on the actual case histories of those in the top five, Kevin and Sharon on those in the middle and Mary on those in the bottom five. We have illustrated the older end of the age range to show what life is like for those teenagers towards the end of their school years.

Alan
Alan is fifteen years old. He is the youngest in his family, having an older brother and two sisters. His parents are in their mid- fifties and both work.

Alan is a happy, good natured lad. He is in good health and wears glasses. He is completely independent in all every day living skills.

He chooses his own clothes, preferring fashionable styles. He makes his own bed and takes a pride in his room. He keeps it tidy and puts his own pop-posters on the wall.

He can run his own bath, wash his hair and cut his nails without supervision but needs help with shaving.

Alan can make himself a drink, a sandwich or simple snack but his mother has not encouraged him to learn to fry food because of the dangers of being splashed by hot fat.

He has good speech and is talkative, always eager to relate the days events when he returns from school. His speech is clear enough for strangers to understand and his parents noticed how much it improved when he moved to a class for children with moderate learning difficulties within an ordinary school.

Alan began to learn to read at six and now can read enough to enjoy comics, magazines and some books. He reads the newspaper daily, the television page and anything else that takes his interest.

Alan can read and write short messages and letters, though he may make some spelling mistakes. He can also write his name and address. He can tell the time using a digital watch, though sometimes makes mistakes.

Alan can add, subtract and multiply numbers up to 20, he knows all units of money and can count simple amounts.

Alan can amuse himself all day long. He particularly enjoys listening to pop music, watching TV, reading, playing games and drawing. He sometimes makes models.

He has both normal and handicapped friends, though he does play mainly with his brother's friends. They spend much of their time outside the house, playing hide and seek, cricket and football. Alan and his brother play board games together. His mother has noticed that he spends more time alone in the house than his brother.

Alan can walk to the school bus and to local shops where he spends his pocket money. He does not belong to any clubs but has quite a full social life with his brother and friends.

He is beginning to show an interest in the opposite sex and enjoys kissing girls at discos. His parents think that he has a reasonable understanding of sexual behaviour as he came in one day and told them the "facts of life" after sex education at school! His parents have never received any advice about Alan's sexual development, though they are not particularly concerned about this.

However, Alan often talks about when he will marry and have children of his own. His mother tries to laugh this off, saying he would not enjoy a nagging wife, but she is concerned about how to "tell him the truth later on". Alan is aware of being handicapped and is sometimes upset by it. Recently he shaved off part of his bushy eyebrows saying that they made him look handicapped even though his brother's are the same. He has a wonderful sense of humour and will impersonate anyone in fun.

As Alan is such a happy good-natured child, his parents do not feel that there have been any negative effects on their family life. They have not been restricted in any way and his brothers and sisters tend to treat him as normal and say he is only "half-handicapped". They are protective of him and love him dearly.

They hope that he will eventually find employment in a normal work situation doing something that is within his capabilities and hope that he will not be taken advantage of in terms of workload or wages. They never envisage him leaving home.

Sharon

Sharon is sixteen and has an elder sister of eighteen and younger brother of thirteen. Her parents are in their late thirties.

Sharon's parents describe her as happy but sometimes too excitable. When she was young she was often ill and had major heart surgery, then grew stronger. Sharon is rather short and overweight so her mother tries to control her diet.

Sharon is well on the way to being fully independent in everyday living skills. She can dress entirely unaided, though her mother still has to put out her clothes. She likes to choose her own new clothes and shows a preference for fashion clothes.

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Sharon is fully continent and independent with toileting, though sometimes needs to be reminded to pull the chain and wash her hands. She can wash, bath and wash her hair without help, though her mother still runs the bath and cuts her nails. She started her periods at eleven and copes with sanitary towels without any help.

Sharon eats tidily, can help herself from serving dishes and her family would happily take her to a restaurant.

She can make a variety of simple snacks including beans on toast, boiled eggs or fried sausage and bacon. She can make hot and cold drinks unaided and use the oven and grill with some supervision.

Sharon began to talk at the age of three and now talks in sentences of five or more words. She speaks clearly and strangers usually have no difficulty understanding her.

Sharon can read a small amount and is reading short fairy tale books for pleasure from a series designed for beginning readers. She cannot read or write a simple message, she can write her name but not address, though she can say it. She knows the days of the week but not the months of the year and cannot tell the time.

Sharon can rote count to 50 and do simple sums using numbers up to 20. She can recognise some coins and notes but cannot count even small amounts of money.

She enjoys drawing, colouring and painting. She spends quite a lot of time alone, although her brother will play with her sometimes. She enjoys watching TV and listening to pop-music. She does not play with friends often except at school. She has no special friend. Sharon likes to go swimming with her sister and she enjoys dancing.

She is only invited to discos or parties about once a year, with other handicapped children, though she belongs to a weekly club for the handicapped.

Sharon is interested in her appearance and in make-up. She has her own bedroom, keeps it tidy, puts up pictures and takes a pride in it.

Sharon's parents can leave her on her own for up to thirty minutes in the house. She is able to cross local roads, walk to school which is very near and to the shops on her own. She has pocket money and spends it on sweets or crisps. She can also buy groceries for her mother if she takes a list.

Sharon is described as rather lazy at times and rather content to do nothing unless prompted. She only swears when cross, when she will also have the occasional tantrum. She copes well with change but is frightened of thunder storms.

Sharon has received some sex education at school and her parents feel she has some understanding. She is interested in boys, but not in any sexual activity as yet, though she masturbates in her own room when bored. Her parents have received no advice about her sexual development or contraception and they are concerned about this and about Sharon's future.

Sharon often says she would like to get married but her parents do not think her capable of coping with the responsibility this would bring, though they would like her to lead as normal a life as possible. She is going to a Further Education College to learn further life skills when she leaves school. Her mother has mixed feelings about this as it will be residential and mean Sharon being away for six weeks at a time, but is realistic enough to admit that Sharon will outlive them and so needs to learn to cope alone. Her parents hope that she will live at home until she wants to leave herself and then hope she will be able to live in a small community unit nearby.

Sharon's mother is pleased with the services for the handicapped in the area in which they live. She felt very positive about all the advice, support and encouragement they had received from the earliest days. Sadly, Sharon has suffered from teasing from local children at times. Her mother believes that she attracts attention to herself because she talks to herself when walking along. She often talks to imaginary playmates and has a variety of these - often named after her school friends.

Kevin

Kevin is sixteen and the eldest of three boys. His brothers are thirteen and seven. His parents are in their early forties.

Kevin's parents describe him as a happy young man. He has a hearing problem, first identified when he was four. He had grommets fitted to drain fluid from his middle ear cavity. He has worn glasses for short sight since the age of ten.

Kevin is very competent at dressing and only needs a little help with laces. He chooses his own clothes each day and likes to choose his own new clothes, though shows no preference for the latest fashions. He makes his own bed but does not keep his room tidy or take any interest in it.

Kevin has good table manners and requires no assistance at mealtimes. He can make himself hot and cold drinks, a sandwich and toast, using the grill unsupervised. Kevin began to talk at 2 years of age. He nows uses three and four word phrases of key words only and his articulation is not very good, so he is not easy to understand. If he is unhappy or frustrated he will not talk at all, only mutter under his breath. When he is not understood he tries hard to describe things with his hands, though he has not been taught any formal sign language.

Kevin can read a few social sight words but not enough to be of any real use to him. He can write his own name but that is all. He can count to 20 and add numbers up to 10. He can recognise some coins but not count any sums of money. He cannot yet tell the time. He can say his name, age, address and birthday correctly and describe the weather adequately, but has not yet mastered the days of the week or the months of the year.

Kevin can amuse himself for several hours. He likes pop-music and enjoys singing along with them, copying their style. He also likes TV and can be left alone in the house for up to an hour if there is a good programme on the television.

Kevin has a couple of normal friends locally, with whom he plays on three or four days of the week with his brothers. He likes football, riding bikes, running and all sports.

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He goes to a club for the handicapped once a week and a playscheme in the school holidays. There are no activities that he can participate in regularly without a member of the family. The main differences that his parents have noticed between Kevin's social life and that of normal teenagers is that he cannot go out on his own, have girl friends or a motor bike like the other lads in the neighbourhood. He is able to walk to the school bus and a local shop alone, but only because these journeys do not involve crossing any roads.

Kevin is a well-behaved young man with no difficult behaviour except swearing, which does upset his parents.

Kevin's parents do not believe that he has any understanding of sexual behaviour nor had any sex education at school. He is showing an interest in the opposite sex but not in sexual activity. He masturbates two or three times a week, and though this distresses his parents, they do not try to stop him.

They have never had any advice on his sexual development and do not know if he can father a child or not. They are concerned for him in the future and afraid that when he plays with normal girls their parents may be anxious that he might be interested in sexual activity.

Kevin's parents say that he has brought them a lot of joy, though they have felt a little tied down at times. They feel his brothers may have had a little less attention but they are very fond of Kevin. They feel their other sons have learned to be more caring and tolerant than they might otherwise have been. It has been difficult to choose holidays that everyone could enjoy, and they feel they would all have benefited from some good short-term care facilities.

When Kevin leaves school, his parents hope that he will have some work to do which will not be too boring, They would like him to be as self- sufficient as possible and to live in a small sheltered hostel from the age of 19 or 20, with some supervision.

Mary
Mary is just seventeen and the youngest of three children. Her parents are in their early fifties.

Mary's parents describe her as a generally happy person. She still needs a lot of help with everyday living skills. She can undress herself but still needs help with fastenings so always has help with dressing each day. She is in good general health and has worn glasses since she was five. She cannot choose her own clothes from the drawers, nor is she interested in fashion clothes when she has new clothes. She takes no interest in her appearance. She does not make her own bed and although she keeps her bedroom exceptionally tidy, she has no interest in putting up photos or posters.

Mary is dry at night, unless she is anxious. She sometimes has an accident if visiting the doctor, dentist or somewhere strange. She will got to the toilet by herself, but needs help to manage her clothes. She can only wipe herself with supervision. She will pull the chain and wash her hands if prompted.

Mary can wash her own face and hands without help, but needs help with all other aspects of self-care. She needs help with cleaning her teeth, bathing and washing hair. In the mornings she requires continual supervision while getting up, though in the evenings she can undress, wash and put on her pyjamas by herself.

Mary started her periods at the age of 12. They are regular but she cannot cope with sanitary towels herself and so always needs supervision.

Mary can eat tidily and competently with the rest of the family and they would be quite happy to take her out to a restaurant with them. She can help herself to a drink or a biscuit without help.

Mary did not begin to speak until she was eight years old. Although she now uses three of four word utterances her articulation is poor and a stranger could not understand her. In general, she is very quiet and will not initiate conversations herself. She has an imaginary friend for company. She talks to this friend for hours and if she does something wrong, will tell her parents that the imaginary friend told her to do it.

Mary cannot read at all, nor write, count or understand money. She likes to colour pictures in colouring books and paint. She knows her name, but not any other personal information. She cannot tell the time or describe the weather.

Mary enjoys listening to pop-music drawing and doing jigsaws and can amuse herself for several hours. She is not allowed to go to the shops alone as she cannot cross the road safely, although she can walk home from the school bus alone. She can be left in the house for up to half an hour on her own.

Mary's parents say that she has no friends. Her mother said that she would dearly love to invite a friend home for her but does not know of anyone. None of her school friends live near. She does not belong to any clubs and goes to a party for the handicapped once a year.

Mary is rather frightened of change and takes time to settle. She sometimes picks holes in her jumpers or picks at the skin on her fingers until it becomes raw. She sometimes has temper-tantrums to get her own way. She shows no interest or awareness of sexual activity and her parents are not concerned about future problems in this area.

Mary's parents feel that they would have benefited from advice on her behavioural problems when she was younger. She is less difficult now than when younger.

Her parents feel that their older children where deprived of their attention because of Mary's needs. They also feel that their social life has been restricted. They do not want to think about the future when they will no longer be able to cope and expect her to go to a training centre when she leaves her special school.

The range of ability

The case histories illustrate the range of ability and dependency that we found in our sample. However, this needs further discussion and clarification and we feel that the distribution of scores for Everyday Living Scores has some interesting significance.

Table II.I shows the frequency distribution of scores for Everyday Living Scores

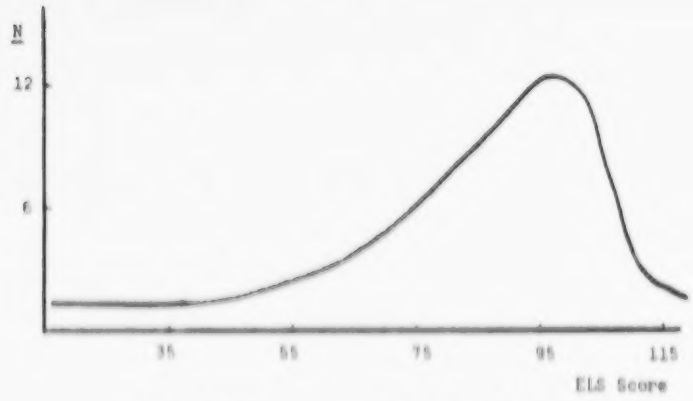

TABLE 11.1 - FREQUENCY DISTRIBUTION FOR EVERYDAY LIVING SKILLS (ELS)

The graph for the distribution of everyday living skills is not a normal distribution.

The majority of the teenagers have scores of 75 and above. This is the main group and the variation in this group probably reflects the interactions of environmental factors we have shown to be significant; for example the quality of schooling, interaction with adults and the material benefits which go with social class position.

The range of abilities of the majority of the teenagers with Down's syndrome and their everday lives are reflected in the first three case histories.

We felt that the very low scorers are a group of much more dependent children who are not part of this main population, but qualitatively different. So we looked closely at the bottom ten young people.

The profoundly handicapped

On the Everyday Living Skill score, these ten young people had scores of 60 or below ranging from 17 to 60.

Table II.2 presents their mean scores as a group on all our measures and gives the mean scores for the entire sample for comparison.

TABLE 11.2 - MEAN SCORES ON ALL MEASURES FOR MOST DEPENDENT TEENAGERS

	ELS	SAS	Leis	Soc con	Soc ind	Gen Beh	Comm
Mean Scores	39.1	11.0	11.3	5.2	0.6	13.2	5.9
Means-full sample	92.1	58.0	18.0	10.1	2.6	8.1	12.1

These figures reveal a very retarded group of young people, even compared to other young people with Down's syndrome. Their achievements are really poor. They are extremely socially isolated and tend to have more behavioural problems than the rest of the group.

80% of this dependent group scored in the moderate or severe range for health problems, compared to 38% of the whole sample.

One lad suffered common illness and infections frequently and very severe attacks of croup throughout childhood. He has limited speech and many behaviour problems including temper-tantrums, head-banging, spitting, hair pulling and thumb sucking. He sits down and refuses to move when out and refuses to dress. At other times he can be too lively and over excited.

Another teenager, a girl, has congenital cataracts resulting in very poor vision and also limited mobility, still tackling stairs two feet at a time. She had no speech until eight years of age, now using one and two words - intelligible to the family but not to strangers. She has some difficult and distressing behaviours including screaming, kicking and head-banging when frustrated or angry. She is frightened of the dark and sudden noises. She likes strict routines and order. She wakes three or four times a night and wanders through the house. Her parents have to get up to her on each occasion and keep the downstairs rooms locked at night. She suffers from pre-menstrual tension which manifests itself in bad tempers and extreme sensitivity according to her parents. These two case histories illustrate many features found in this group of very disabled young people.

The health problems include five with poor eyesight, three with severe heart-problems and a higher frequency of all common ear, throat,skin and stomach infections. Parents reported poor mobility for half this group, four still climbing stairs with two feet on each stair, one only able to climb stairs on hands and knees.

Of the ten young people eight had very poor communication. Most did not begin to speak until seven or eight years, still only use one or two word utterances and are very difficult to understand. The other two had no speech at all.

The range of behaviour problems included tantrums, hair-pulling, spitting, destructive behaviour and screaming when frustrated for over half the group. Four were frightened of the dark, loud noises and change. Three liked order to an obsessional degree and disliked change. Four presented a rather helpless, passive and inactive picture. The remainder were more likely to be restless, to wander and become difficult. Half the group had imaginary friends and talked regularly to them.
Four of this group were still incontinent all or much of the time and two more wet themselves when anxious or distressed. Six had severe sleep problems, getting up in the night and wandering, getting into parents beds and two remarked that their young people did not need to sleep.

Three parents reported obstinate behaviour, mainly refusing to walk, sitting down in the street and refusing to get out of a car. Managing a teenager who sits on the pavement and refuses to get up is obviously not easy. Half the group of families had no relatives or friends willing to help with their son or daughter and only half had short-term care available and for two of these it was only a holiday break once a year. Most of these families were coping with a great deal of resilience and described their teenager as much loved in the family, despite their degree of handicap.

While these young people are a minority and much more disabled than the majority of young people with Down's syndrome, they must not be overlooked. They are much more biologically damaged than the rest of the group and it is important that professionals and parents recognise that there are some youngsters with Down's syndrome who will be as retarded as this.

It is possible that the lack speech in this group is the result of peripheral hearing or central auditory perceptual problems which have not been detected.

These families should be identified and offered more practical support and relief.

The teenagers own perceptions

We mentioned in the introduction that Anderson & Clarke (1982) in their study of teenagers with a physical handicap had asked the teenagers themselves how they viewed their current lives and their future. We decided not to attempt this with our teenagers. We know that some of the more able ones would have been able to give us their own views, but that the majority would not be able to - at least verbally.

However, we do feel that this is an important issue and an area for further research. It will need the development and evaluation of methods such as role-play to enable the less able to express themselves.

We did ask some parents (just over half the sample) about their teeenager's perception of their handicap. Of these 52 parents, just over half reported that they did not feel their teenager felt different or handicapped. In fact some thought other children handicapped but not themselves, for example:

"She does not realise that she is mentally handicapped. When she first met another Down's syndrome child, she made it plain that she thought the child different from "us". She continues to perceive the situation in this way".

However, 38% of parents reported that their teenager definitely was aware of being different and felt affected by it, as the followng quotes illustrate:

"I don't want to go out - people will look at me" (from an eleven year old).

"He is very self conscious and aware of being different. In particular, he is concerned about his facial features. He will often look in the mirror and try to alter his appearance. He will cry if anyone laughs at him."

"She has recently become acutely aware of being different (at 13) She first noticed different facial features from normal children when looking at a professionally taken photograph of herself. She saw herself as ugly and then frequently cried." This teenager's mother coped with this situation by telling her daughter that she was a "special person" and loved in her own right and that all people have physical differences in appearance. Now the daughter actively looks for pecularities in other people.

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The main conclusions from the survey

The teenager

Our results show that the majority of teenagers are warm, happy, cheerful and much loved members of their families. Most are not difficult to live with, as shown from the figures for difficult behaviours and the reluctance of most families to part with their son or daughter.

Most of the teenagers are well on the way to independence in all aspects of personal care and hygiene, but few could prepare snacks or meals.

While most had some speech and could be understood by parents and teachers, communication was clearly a problem for many once they were in the outside world. Poor communication creates difficulties in dealing with feelings and half the group still played out their worries in fantasy play. Poor communication is bound to limit the way they can relate to others in social situations and establish friendships.

Very few teenagers had any useful reading, writing, number or money skills. Few could tell the time and only a minority knew essential personal information well enought to cope if they were lost.

We would describe most of the teenagers as socially isolated, with few real friends or social activities outside school. While they had the normal range of teenage interests they were rarely able to actively pursue them by going to discos or playing sport out of school. Most of their time was spent in passive and solitary activity. Most were quite unable to cross roads or go about the neighbourhood on their own. About half created fantasy friends to talk to and to play games with. Most were very dependent on their families for their social lives.

Health was generally quite good at this age. Most did not suffer many more infections that normal. Some, had permanent impairment to hearing, heart or vision. About 16% were rated as having severe persistent health problems and these had affected their development. We found no evidence of mental illness.

Sexual development was proceeding with few problems though parents were anxious to receive more information on this topic.

There is a wide variation in development among the teenagers, with some rather more able than this overview suggests but some were much more dependent. The summary above picks out the issues which are relevant for some 80% of the group, some 10% being more able and the remaining 10% much more handicapped.

Families

The families are clearly a resourceful and resilient group of people. Most have bought up their teenager with little help from services other than schools. Despite the social dependency of their teenagers, because they cannot be left unsupervised at home nor go out unsupervised, most families are not complaining. The majority do not think that family life has suffered excessively and neither have brothers and sisters.

The future after school is an area of concern. Families hoped that their young people could find work which would be interesting and satisfying within their capabilities. They did not want them to spend many years in an unstimulating environment.

Half the families did not want their young person to ever leave home and if they did, then the majority wanted to see them settled in small, homely surroundings near the family with as much privacy and independence as possible. Being with their friends was also an important requirement.

Factors affecting development

It is clear from our data, that the teenager's progress is affected both by the quality of the environment that they grow up in and by biological factors. Ill-health is clearly a major problem for some and tends to lead to more severe handicap and dependency. We would suggest that the slight disadvantage the boys seem to have with language development is also a biological effect.

We did not find significant differences in the progress of the boys and girls in any other area of development. They did tend to be a little behind in some self-help areas but not enough to be significantly behind. They were ahead of the girls in achieving social independence outside the home. Our findings agree with those of Shepperdson who also reports no significant sex differences.

Maybe we differ from other authors (Carr 1985, Gath, 1985) who do report that boys are more delayed, because we have used different measures. Both Gath and Carr report the significant difference on the basis of IQ scores, which are going to be more sensitive to being affected by language delay.

We have not used any IQ tests, but have looked directly at the acquisition of skills relevant to everyday life. Right across the range, boys are doing as well as girls, except on language.

All the teenagers are improving with age. This is seen not only in an increase in skills but also in a decrease in difficult behaviour. Only social competence and persistent health problems were not improving with age.

The teenagers were showing the benefits that come from being in a position in the family that probably enabled them to have more adult attention. They also show benefits from the advantages which come from higher social class.

Some schools were providing more effective learning environments than others as evidenced in the higher performance of the teenagers in some schools. The environment at school also had a significant effect on difficult behaviour and communication skills.

Very poor communication increased the likelihood of difficult behaviour. There was a relationship between the teenager's progress and how positively the family felt about them. It is possible that more positive families have encouraged more progress.

Implications for parents and services

The majority of parents are clearly doing a first rate job in bringing up happy teenagers who can care for themselves at home.

Areas that parents need to perhaps spend more time on are the more difficult areas of self-care like nail cutting and hair washing. They certainly need to consider spending time teaching some simple cooking, and household skills.

Very few could be left unsupervised, not because they would harm themselves or get into mischief, but because they do not have the practical skills to cope. Very few could write a message or deal with any emergency - nor fix themselves a snack.

Perhaps, as parents we do not think enough about the fact that our children are now adolescent and need to move away from the family. Ordinary teenagers often want independence too early and need restraining. Our teenagers are going to need help and deliberate encouragement.

If our teenagers are going to make friends and move into the social world, we are going to have to work at it. It will need a conscious effort on the part of families to seek out suitable social and leisure activities and to help build friendships.

This social contact is so important in helping to build the self- confidence of our teenagers and to give them skills to enable them to take their place in the community as adults.

If our teenagers are going to learn to cross roads and go about the neighbourhood safely, we are going to have to work at teaching them. This will involve taking risks - a different issue, but one that parents of all teenagers face when they want more independence. They can only begin to learn to be responsible for themselves if given a chance to practise - in small steps. Each new step that the teenager masters will also contribute to his self-confidence and sense of worth.

It might be worth thinking about asking for the help of local teenagers. Many young people are sensitive, caring and eager to help those less able than themselves. Local Guides, Scouts or Church groups might respond positively to setting up a befriending scheme and pairing one or two ordinary teenagers with a handicapped teenager. Jodie Walsh describes ideas which could be adopted in her book "Let's Make Friends."

Most teenagers were hampered by inadequate speech. Parents need to be aware of this and make a conscious effort to encourage more adequate speech, bearing in mind that what they manage to understand at home is probably not going to be understood by strangers. Parents may unwittingly be contributing to the delay as they often repeat things for their teenagers or interpret for them in social situations, rather than making the young person manage on their own.

Certainly one of the author's noticed a significant improvement in her daughter's speech when she left home for further education. She now had no one to help out and had to try harder for herself. Her articulation improved and so did her vocabulary. We also realised that at home she often did not need to speak. She knew all the routines and we met her needs before she asked!

Sometimes language teaching seems to focus too much on teaching language for "asking for things" or "obtaining information". Few of our teenagers had reached the stage of appreciating the social function of language. They did not have conversational skills. Some parents actually commented that their young person only spoke when they needed something.

Many teenagers did not know how to initiate an ordinary conversation with an acquaintance or a stranger. They would not know how to begin to make friends by exchanging pieces of personal information about themselves, like their names, where they live and where they go to school; nor were they aware of the social comments that oil the wheels of social relationships.

We felt that our daughter had taken an enormous step forward into the social world the rest of us take for granted when we heard her initiate an interaction for the first time. As her cousin came in, she said "Where you been Evie".

A year or so later she made another step forward when she began to use compliments like "You look nice Granny" as her grandmother came out of the house in a new hat and coat and on another occasion "Good cook, Granny" when sitting down to lunch.

It is all too easy - even in sensitive families, for life to go on around the person with a handicap with them only on the fringe of it - unable to really join in the conversations or fully participate in the activities of the rest of the family.

Schools

Our data clearly shows that schools matter. The quality of the teaching and the expectations for behaviour are related to progress in the teenagers.

Schools should focus on communication skills right from the start and continue to work at them as an area of high priority. The skills of a speech therapist are essential in every school, ideally on a full-time basis. The impact of poor communication on the social and emotional lives of the teenagers as well as on every other area of development cannot be overemphasised.

Secondly, schools need to pay more attention to practical everyday living skills if they are to reach a level which is useful to the teenager. Much more liaison with parents is needed to help these young people to learn to cook, shop, cross roads and cope with emergencies.

Much more attention should also be given to teaching relevant reading and writing skills - for practical use, not only to shop and cook, but to be able to look up TV programmes, write a postcard, sign names and to read a letter. The teaching of reading and writing - using an appropriate vocabulary - should begin much earlier than is common practise at present.

Much more attention should be paid to teaching money skills from the start of the child's school career in relevant ways. Each school could have a "shop", "post office" and "bank" in daily operation. Here the child can practise writing lists and signing their names in addition to learning to understand and use money, in the appropriate setting.

Working closely with parents in all these areas is going to greatly increase the effectiveness of the work done in schools. Parents spend many more hours with their child in a week, than the teacher. They can engage in language teaching as a continuous activity, given the right advice.

All the skills being taught in schools need to be practised in the real world - at home and out in the neighbourhood if they are to develop to a level that is useful.

Recent studies of all children have demonstrated the value of involving parents in the teaching of reading.

Parents who have been involved closely in their children's pre- school education often remark on the difference in involvement once their child starts school. They feel there is much they could be doing to help the child but need guidance from school on what to do and how to do it.

Schools could also pay more attention to the development of motor skills. Music and movement and gym activities can greatly increase the control and co-ordination for these young people. Fine motor skills should also be developed from the earliest days, especially with writing and drawing in mind.

Good motor co-ordination can lead to be being able to engage in enjoyable social activities, such as dancing, swimming and football. Skill in one or other of these areas will not only open up a route to social activities and friends, success will also greatly contribute to the young persons self-confidence.

Unfortunately many special schools do not have gymnasiums and apparatus adequate for teenagers nor in any way comparable to those to be found in the average comprehensive school. Few special schools can field a football team or give the lads real experience of the competitive game with normal lads. Few special schools will have the benefit of a specialist music teacher, drama teacher or physical education teacher.

Health care

These teenagers require first class health care and regular screening for the health problems that may arise. The fact that we found a social class difference suggests that not all the health problems are inevitable.

Keeping free of infection and early treatment when infection does occur will reduce coughs, colds, throat and ear infections.

Regular health screening, every three years, including checks for thyroid function, hearing and vision should be routinely offered to all with Down's syndrome. Preventive medicine is sure to be cost effective in the end and to greatly improve the quality of life.

The future

The majority of parents wanted useful occupations for their young people. They would like them to work within their capacity at jobs which were interesting and would keep them alert. They did not want them exploited as cheap labour, nor to spend their days doing boring, repetitive tasks.

Parents identified the importance of meaningful occupation in giving the young person dignity and self-respect. A useful guide to helping the young person achieve the necessary work skills are Whelan and Speake's books, "Getting to Work" and "Learning to Cope".

Parents put leisure interests at the top of their list for more services. They were aware of the limited social lives of their teenagers and the lack of suitable facilities.

It will need a deliberate effort on the part of parents, schools and society in general if these young people are to be integrated into the real world of their own age-group. Befriending schemes will be needed such as those described by Jodie Walsh (1986) in her book "Lets Make Friends". Ideas for involving the young person in leisure activities can be found in Jeffree & Cheseldine (1984) book, "Let's Join in". (All these books are published by Souvenir Press and full references are given in reference list.)

The issues we are highlighting almost certainly apply to many other severely-handicapped teenagers as the evidence of Cheseldine & Jeffree (1981) suggests.

Our conclusions from our data are strengthened by the fact that there is considerable agreement between our data and that reported by Carr, Gath and Shepperdson.

Many writers are already aware of the need to teach social skills and encouraging reports of teaching programmes are appearing in the professional literature, ie Keogh et al (1985) on enhancing leisure skills, Rynders et al (1980) and Strain and Odom (1986) on enhancing interaction between handicapped and non-handicapped teenagers. These are all American studies, suggesting that the USA may be ahead of us in tackling these issues in a practical way.

Quality of life

It was clear from the time we spent talking to families and from all they told us on the questionnaires, that what mattered most to them was the quality of life that their son or daughter experienced.

Parents are not unrealistic, they are aware of their teenagers limitations. They are also aware that the outside world can be cruel, lonely and hostile place if you are a little different or a little less capable than most people.

They wanted future homes for their young people to offer a family atmosphere with love, security, privacy, friendships and contact with their families.

They wanted occupations which would also enhance their quality of life by providing them with something interesting and satisfying to do. We do not think that any of these aims are unrealistic.

We know that many of the young people could greatly improve on the level of their skills where we found them to be inadequate for independent living.

Most young people with Down's syndrome are able to achieve far more than most professionals still realise.

We do not believe that Nigel Hunt, Cathy Hebden or Sarah Duffen are exceptional in the sense that they were simply born more able than most. What shines through their stories of success is the determination of their parents to love them, educate them and to never believe that any target was unattainable (which usually meant ignoring professional advice).

Nigel became the first person with Down's syndrome to write a book (Hunt 1967). Cathy became the first to achieve a Duke of Edinburgh Gold Award (Hebden 1985) and Sarah become the first person to pass a test to drive a car (Woman, August 1987).

Sadly many parents soon realise that they not only have a special child who needs some extra time and attention to bring up, they also have to battle with society and the services it offers on behalf of that child if they want the best for them. The forward to Nigel Hunt's book, written by his father, and Joan Hebdens book should be compulsory reading for all professionals.

We feel that many schools could achieve much higher standards in all areas of the curriculum. Health care and family support services could be much better. We know that many families would be willing to make much more use of care facilities if they felt that the quality of care offered was actually acceptable.

The findings of our study have implications for our teenagers which require action now. They also have implications for services from the birth of a child with Down's syndrome.

Parents need positive support and accurate information from the outset. Children need good health care, including physiotherapy, speech therapy and pre-school education from the first months of life. They need expert education throughout childhood which should involve parents as equal partners and should not remove them entirely from the world of their peers if they are to achieve their potential and take their place as useful and valued members of society.

PUBLICATIONS USEFUL TO TEENAGERS AND THEIR PARENTS

The IYC Trust Notebook - for school-leavers with special needs. Obtainable from: National Children's Bureau, Voluntary Council for Handicapped Children, 8 Wakley Street, London EC1V 7QE

After 16 - what next?
Published by: The Family Fund, Joseph Rowntree Memorial Trust PO Box 50, York YO1 1UY.

Disability Rights Handbook
Obtainable from: The Disability Alliance, 25 Denmark Street, London, WC2 9NJ.

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APPENDIX OF

STATISTICAL DATA

CHAPTER 3 - EVERYDAY LIVING SKILLS

1. Sex Differences - Boys compared to Girls

Results of Mann-Whitney U - Wilcoxon Rank Sum W Tests for each set of scores

(a) Dressing

Group	Mean Rank	Cases
Boys	45.49	50
Girls	45.51	40

U	W	z		
999.5	1820.5	-0.0041	0.9968	n.sig

(b) Toileting

Group	Mean Rank	Cases
Boys	43.96	50
Girls	47.42	40

U	W	z	p	
923.0	1897.0	-0.6306	0.5283	ns

(c) Personal Care

Group	Mean Rank	Cases
Boys	41.74	50
Girls	50.20	40

U	W	z	p	
812.0	2008.0	-1.5289	0.1263	n.sig

(d) Meals

Group	Mean Rank	Cases
Boys	43.24	50
Girls	48.32	40

U	W	z	p	
887.0	1933.0	-0.9618	0.3361	ns

(e) Snacks

Group	Mean Rank	Cases
Boys	38.53	50
Girls	54.21	40

U	W	z	p	
651.5	2168.5	-2.8350	0.0046	sig

(f) Table laying etc

Group	Mean Rank	Cases
Boys	40.96	50
Girls	51.17	40

U	W	z	p	
773.0	2047.0	-1.8774	0.06	ns

(g) Total ELS Score

Group	Mean Rank	Cases
Boys	43.39	50
Girls	48.14	40

U	W	z	p	
894.5	1925.5	-0.8570	0.3914	ns

2. Age Effects - Under 14's compared to over 14's
Results of Mann-Whitney U - Wilcoxon Rank Sum W Tests for each set of scores

(a) Dressing

Group	Mean Rank	Cases
Under 14	40.83	46
Over 14	50.39	44

U	W	z	p
797.0	2217.0	-17390	0.0820 ns

(b) Toileting

Group	Mean Rank	Cases
Under 14	41.03	46
Over 14	50.17	44

U	W	z	p
806.5	2207.5	-1.6730	0.0943 ns

(c) Personal Care

Group	Mean Rank	Cases
Under 14	40.84	46
Over 14	50.38	44

U	W	z	p
797.5	2216.5	-1.7340	0.0829 ns

(d) Meals

Group	Mean Rank	Cases
Under 14	41.30	46
Over 14	49.89	44

U	W	z	p
819.0	2195.0	-1.6330	0.1025 ns

(e) Snacks

Group	Mean Rank	Cases
Under 14	37.82	46
Over 14	53.53	44

U	W	z	p
658.5	2355.5	-2.8585	0.0043 sig

(f) Table-laying etc

Group	Mean Rank	Cases
Under 14	42.93	46
Over 14	48.18	44

U	W	z	p
894.0	2120.0	-0.9701	0.3320 ns

(g) Total ELS score

Group	Mean Rank	Cases
Under 14	39.75	46
Over 14	51.51	44

U	W	z	p
747.5	2266.5	-2.1358	0.0327 sig

3. Effect of Ill-health on every-day living skills - see Appendix Chapter 8

4. Effect of family position on ELS - see Appendix Chapter 10

5. Effect of school on ELS - see Appendix Chapter 5

6. Effect of social class on ELS - see Appendix Chapter 10

7. See intercorrelations in Appendix Chapter 3.
ELS is significantly positively correlated with communication, school achievement and all social scores.
ELS is negatively correlated with difficult behaviour scores.
ELS shows a small significant negative correlation with the measure of family attitude.

CHAPTER 4 - COMMUNICATION

Results of Mann-Whitney U-Wilcoxon Rank Sum W Tests for each set of scores.

1. Sex Differences Boys compared to girls

Group	Mean Rank	Cases
Boys	38.76	50
Girls	53.92	40

U	W	z	p
663.0	2157.0	-2.7569	0.0058 sig

2. Age Effect Under 14 compared to over 14

Group	Mean Rank	Cases
Under 14	42.26	46
Over 14	48.89	44

U	W	z	p
863.0	2151.0	-1.2117	0.02256 ns

3. Effect of ill-health on communication See Appendix Chapter 8
Children in poor health have significantly lower communication scores.

4. Effect of family position on communication - see Appendix Chapter 10

5. For intercorrelations with other scores see Appendix Chapter 3
Communication scores show a significant positive correlation with ELS, SAS and all social scores. Communication scores show a significant negative correlation with difficult behaviour, and with the measures of effects on family life and family attitude.

CHAPTER 4 - FANTASY FRIENDS AND SELF-TALK

Results of Mann-Whitney U-Wilcoxon Rank Sum W Tests for each set of scores

1. Communication score and fantasy

Group	Mean Rank	Cases
No fantasy	35.13	34
Fantasy	31.77	32

U	W	z	p
488.5	1016.5	-2.7181	0.4727 ns

2. Leisure score and fantasy

Group	Mean Rank	Cases
No fantasy	29.99	34
Fantasy	37.23	32

U	W	z	p
424.5	1191.5	-1.5366	0.1244 ns

3. Fantasy and social contact score

Group	Mean Rank	Cases
No fantasy	34.59	34
Fantasy	32.34	32

U	W	z	p
507.0	1035.0	-0.4763	0.6339 ns

4. Independence and fantasy

Group	Mean Rank	Cases
No fantasy	34.37	34
Fantasy	32.58	32

U	W	z	p
514.5	1042.5	-0.3967	0.6916 ns

5. Fantasy and difficult behaviour

Group	Mean Rank	Cases
No fantasy	26.54	34
Fantasy	40.89	32

U	W	z	p
307.5	1308.5	-3.0426	0.0023 sig

6. Fantasy and school achievement SAS

Group	Mean Rank	Cases
No fantasy	33.59	34
Fantasy	33.41	32

U	W	z	p
541.0	1069.0	-0.0385	0.9693 ns

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8. Fantasy and Everyday Living Skills (ELS)

Group	Mean Rank	Cases
No fantasy	36.29	34
Fantasy	30.53	32

U	W	z	p
449.0	977.0	-1.2192	0.2228 ns

CHAPTER 5 - SCHOOL ACHIEVEMENT

1. Sex Differences Boys compared to Girls. Results of Mann-Whitney U-Wilcoxon Rank Sum W Tests for each set of scores.

(a) Reading

Group	Mean Rank	Cases
Boys	42.69	50
Girls	49.01	40

U	W	z	p
859.5	1960.5	-1.1528	0.2490 ns

(b) Writing

Group	Mean Rank	Cases
Boys	43.06	50
Girls	48.55	40

U	W	z	p
878.0	1942.0	-1.0024	0.3161 ns

(c) Arithmetic

Group	Mean Rank	Cases
Boys	44.48	50
Girls	46.77	40

U	W	z	p
949.0	1871.0	-0.4153	0.6779 ns

(d) Money

Group	Mean Rank	Cases
Boys	44.58	50
Girls	46.65	40

U	W	z	p
954.0	1866.0	-0.3843	0.7008 ns

(e) General Knowledge

Group	Mean Rank	Cases
Boys	43.85	50
Girls	47.56	40

U	W	z	p
917.5	1902.5	-0.6706	0.5025 ns

(f) Total School Achievement Score

Group	Mean Rank	Cases
Boys	43.10	50
Girls	48.50	40

U	W	z	p
880.0	1940.0	-0.9745	0.3298 ns

2. Age Improvements - Under 14 compared to over 14. Results of Mann-Whitney U-Wilcoxon Rank Sum W Tests for each set of scores

(a) Reading

Group	Mean Rank	Cases
Under 14	43.35	46
Over 14	47.75	44

U	W	z	p
913.0	2101.0	-0.8075	0.4194 ns

(b) Writing

Group	Mean Rank	Cases
Under 14	43.38	46
Over 14	47.72	44

U	W	z	p
914.5	2099.5	-0.7964	0.4258 ns

(c) Arithmetic

Group	Mean Rank	Cases
Under 14	41.38	46
Over 14	49.81	44

U	W	z	p
822.5	2191.5	-1.5339	0.1251 ns

(d) Money

Group	Mean Rank	Cases
Under 14	42.02	46
Over 14	49.14	44

U	W	z	p
852.0	2162.0	-1.3287	0.1840 ns

(e) General Knowledge

Group	Mean Rank	Cases
Under 14	40.42	46
Over 14	50.81	44

U	W	z	p
778.5	2235.5	-1.8866	0.0592 sig

(f) Total School Achievement Score

Group	Mean Rank	Cases
Under 14	41.25	46
Over 14	49.94	44

U	W	z	p
816.5	2197.5	-1.5782	0.1145 ns

3. Effect of ill-health on school achievement - see analysis p

4. Effect of family position on school achievement - see Appendix Chapter 8

5. Effect of socio economic status on school achievement see Appendix Chapter 10

6. Spearman Correlation Coefficients for Full Sample N=90

	Communication	Leisure Activities	Social Contact	Social Independence	Difficult Behaviour	Everyday Living ELS
Leisure Activities	0.32 (p=0.001)					
Social Contact	0.23 (p=0.008)	0.4 (p 0.001)				
Social Independence	0.28 (p=0.004)	0.46 (p 0.001)	0.5 (p 0.001)			
Difficult Behaviour	-0.26 (p=0.006)	-0.09 (ns)	-0.09 (ns)	-0.19 (p 0.001)		
Everyday Living Total Score	0.54 (p=0.000)	0.46 (p 0.001)	0.36 (p 0.000)	0.5 (p 0.000)	-0.43 (p 0.000)	
School achievements Total score SAS	0.58 (p=0.000)	0.62 (p 0.000)	0.33 (p 0.000)	0.46 (p 0.000)	-0.14 (p=0.08)	0.60 (p= 0.000)

CHAPTER 6 - SOCIAL ACTIVITIES, LEISURE AND FRIENDSHIPS

Results of Mann-Whitney U-Wilcoxon Rank Sum W Tests for each set of scores

1. Sex differences - Boys compared to girls

a) Leisure activities

Group	Mean Rank	Cases
Boysa	44.91	50
Girls	46.24	40

U	W	z	p
970.5	1849.5	-0.2401	0.8102 ns

b) Social Contact

Group	Mean Rank	Cases
Boys	45.75	50
Girls	45.19	40

U	W	z	p
987.5	1807.5	-0.1019	0.9189 ns

c) Social independence

Group	Mean Rank	Cases
Boys	45.73	50
Girls	45.21	40

U	W	z	p
988.5	1808.5	-0.0970	0.9228 ns

2. Age Effects - under 14's compared to over 14's

a) Leisure activities

Group	Mean Rank	Cases
Under 14	46.23	46
Over 14	44.74	44

U	W	z	p
978.5	1968.5	-0.2710	0.7864 ns

b) Social Contact

Group	Mean Rank	Cases
Under 14	47.80	46
Over 14	43.09	44

U	W	z	p
906.0	1896.0	-0.8588	0.3904 ns

c) Social independence

Group	Mean Rank	Cases
Under 14	42.17	46
Over 14	48.98	44

U	W	z	p
859.0	2155.0	-1.2823	0.1998 ns

3. For intercorrelations with other scores see Appendix Chapter 3

All social scores show a significant positive correlation with ELS, SAS and communication scores. All social scores show a significant negative correlation with the measure of family attitude. Social contact scores are also negatively correlated with effect on the family and effect on siblings.

CHAPTER 7 - GENERAL BEHAVIOUR AND PERSONALITY

Results of Mann-Whitney U-Wilcoxon Rank Sum W Tests for each set of scores

Difficult Behaviour Scores

1. Sex differences - Boys compared to girls

Group	Mean Rank	Cases
Boys	47.66	50
Girls	42.80	40

U	W	z	p
829.0	1712.0	-0.8799	0.3789 ns

2. Effect of age - Under 14's compared to over 14's

Group	Mean Rank	Cases
Under 14	50.18	46
Over 14	40.60	44

U	W	z	p
796.5	1786.5	-1.7453	0.0808 (approaching sig)

3. For relationship to ill-health Appendix Chapter 8. Children with poor health scores were significantly worse on difficult behaviour scores also.

4. For intercorrelation with other scores Appendix Chapter 3. Difficult behaviour is significantly correlated with poor communication and with low self-help scores.

5. For relationship with fantasy and self-talk see Appendix Chapter 4

Those teenagers with fantasy friends or self-talk showed significantly higher scores on difficult behaviour than those without.

CHAPTER 8 - PHYSICAL DEVELOPMENT AND HEALTH

Results of Mann-Whitney U-Wilcoxon Rank Sum W Tests for each set of scores

Illness Scores

1. Sex differences - Boys compared to girls 2. Age Differences

Group	Mean Rank	Cases
Boys	45.76	50
Girls	45.17	40

U	W	z	p	
987.0	1807.0	-0.1098	0.9126	ns

Group	Mean Rank	Cases
Under 14	41.63	46
Over 14	49.55	44

U	W	z	p	
834.0	2180.0	-1.4945	0.1350	ns

Effects of illness on development

Results of Kruskal-Wallis 1 Way Anova

a) Effect of Illness on Communication Score

Group	Mean Rank	Cases
No health problem	54.57	30
Minor health "	47.77	26
Moderate " "	41.35	20
Severe " "	27.79	14

Chi-square	Significance	
10.9122	0.0122	sig*

b) Effect of Illness on Leisure Score

Group	Mean Rank	Cases
No health problem	43.88	30
Minor health "	49.33	26
Moderate " "	40.75	20
Severe " "	48.64	14

Chi-square	Significance	
1.5440	0.6722	ns

c) Effect of Illness on Social Contact Score

Group	Mean Rank	Cases
No health problem	53.57	30
Minor health "	40.25	26
Moderate " "	40.40	20
Severe " "	45.25	14

Chi-square	Significance	
4.7089	0.1944	ns

d) Effect of Illness on Social Independence Score

Group	Mean Rank	Cases
No health problem	48.82	30
Minor health "	43.00	26
Moderate " "	47.35	20
Severe " "	40.39	14

Chi-square	Significance	
1.4629	0.6909	ns

e) Effect of Illness on Difficult Behaviour Score

Group	Mean Rank	Cases
No health problem	35.52	30
Minor health "	52.02	26
Moderate " "	48.82	20
Severe " "	50.04	14

Chi-square	Significance	
6.7918	0.0788*	Approaching sig.

f) Effect of Illness on ELS Score

Group	Mean Rank	Cases
No health problem	51.87	30
Minor health "	47.46	26
Moderate " "	37.10	20
Severe " "	40.21	14

Chi-square	Significance	
4.5729	0.2059	ns

g) Effect of Illness on School Achievement Score

Group	Mean Rank	Cases
No health problem	44.90	30
Minor health "	51.62	26
Moderate " "	43.20	20
Severe " "	38.71	14

Chi-square	Significance
2.5407	0.4680 ns

h) Effect of Social Class on Illness Scores

Group	Mean Rank	Cases
I & II	35.14	25
IIn & IIIm	41.43	35
IV & V	50.33	23

Chi-square	Significance
4.7889	0.0912 ns

Effects of Obesity on Teenagers Development

Results of Mann-Whitney U-Wilcoxon Rank Sum W Tests for each set of scores

(a) Effect of Obesity on Communication Score

Group	Mean Rank	Cases
Not overweight	42.89	51
Overweight	47.63	38

U	W	z	p
861.5	1817.5	-0.8985	0.3689 ns

(b) Effect of Obesity on Total Everyday Living Skill Score ELS

Group	Mean Rank	Cases
Not overweight	43.75	51
Overweight	46.68	38

U	W	z	p
905.0	1774.0	-0.5311	0.5954 ns

(c) Effect of Obesity on Total School Achievement Score

Group	Mean Rank	Cases
Not overweight	41.62	51
Overweight	49.54	38

U	W	z	p
796.5	1882.5	-1.4310	0.1524 ns

(d) Effect of Obesity on Leisure Activities Scores

Group	Mean Rank	Cases
Not overweight	44.56	51
Overweight	45.59	38

U	W	z	p
946.5	1732.5	-0.1871	0.8516 ns

(e) Effect of Obesity on Social Contact Score

Group	Mean Rank	Cases
Not overweight	45.18	51
Overweight	44.76	38

U	W	z	p
960.0	1701.0	-0.0749	0.9403 ns

(f) Effect of Obesity on Social Independence Scores

Group	Mean Rank	Cases
Not overweight	43.26	51
Overweight	47.33	38

U	p W	z	p
880.5	1798.5	-0.7625	0.4457 ns

(g) Effect of Obesity on Difficult Behaviour Score

Group	Mean Rank	Cases
Not overweight	43.60	51
Overweight	46.88	38

U	W	z	p
897.5	1781.5	-0.5950	0.5518 ns

CHAPTER 10 - THE FAMILY

Analyses of the effects of family position on the teenagers development.

Results of Kruskal-Wallis 1-way ANOVA for each set of scores.

1. Effect of family position on communication score

Group	Mean Rank	Cases
Only child	47.69	8
Eldest	40.93	21
Middle	29.40	10
Youngest	43.44	43

Chi-square	Significance
3.4815	0.3232 ns

2. Effect of family position on general knowledge score

Group	Mean Rank	Cases
Only child	52.38	8
Eldest	36.50	21
Middle	27.65	10
Youngest	45.14	43

Chi-square	Significance
6.9945	.0.0721 ns (approaching significance)

3. Effect of family position on leisure activities score

Group	Mean Rank	Cases
Only child	45.56	8
Eldest	31.90	21
Middle	32.90	10
Youngest	47.43	43

Chi-square	Significance
7.6536	0.0537 *sig

4. Effect of family position on social contact scores

Group	Mean Rank	Cases
Only child	41.88	8
Eldest	39.98	21
Middle	35.20	10
Youngest	43.64	43

Chi-square	Significance
1.1434	0.7666 ns

5. Effect of family position on social independence scores

Group	Mean Rank	Cases
Only child	37.63	8
Eldest	33.40	21
Middle	40.45	10
Youngest	46.42	43

Chi-square	Significance
4.8247	0.1851

6. Effect of family position on difficult behaviour scores

Group	Mean Rank	Cases
Only child	37.81	8
Eldest	37.14	21
Middle	57.35	10
Youngest	42.02	43

Chi-square	Significance
2.6448	0.4497

7. Effect of family position on ELS score

Group	Mean Rank	Cases
Only child	45.81	8
Eldest	38.17	21
Middle	35.40	10
Youngest	43.74	43

Chi-square	Significance
1.7134	0.6340 ns

8. Effect of family position on total School Achievement Scores

Group	Mean Rank	Cases
Only child	49.38	8
Eldest	38.43	21
Middle	32.60	10
Youngest	43.60	43

Chi-square	Significance
2.9573	0.3983

10. Effect of family position on illness scores

Group	Mean Rank	Cases
Only child	27.56	8
Eldest	45.00	21
Middle	44.85	10
Youngest	41.60	43

Chi-square	Significance
3.6959	0.2962

Chapter 10

Analyses of the effects of socio-economic status on the teenagers development

Results of Kruskal-Wallis 1-way ANOVA for each set of scores.

1. Effect of socio-economic status on communication scores

Group	Mean Rank	Cases
I & II	39.32	25
IIIn & IIIm	49.40	35
IV & V	33.65	23

Chi-square	Significance
6.4662	0.0394 *sig

2. Effect of socio-economic status on total everyday living scores ELS

Group	Mean Rank	Cases
I & II	44.20	25
IIIn & IIIm	45.29	35
IV & V	34.61	23

Chi-square	Significance
3.0239	0.2205 ns

3. Effect of socio-economic status on total school achievement score SAS

Group	Mean Rank	Cases
I & II	46.48	25
IIIn & IIIm	47.84	35
IV & V	28.24	23

Chi-square	Significance
10.4191	0.0055 *sig

4. Effect of socio-economic status on reading score

Group	Mean Rank	Cases
I & II	48.24	25
IIIn & IIIm	47.26	35
IV & V	27.22	23

Chi-square	Significance
12.2405	0.0022 *sig

5. Effect of socio-economic status on writing scores

Group	Mean Rank	Cases
I & II	47.28	25
IIIn & IIIm	44.34	35
IV & V	32.70	23

Chi-square	Significance
5.0534	0.0799 *approaching sig

6. Effect of socio-economic status on arithmetic scores

Group	Mean Rank	Cases
I & II	46.92	25
IIIn & IIIm	46.67	35
IV & V	29.54	23

Chi-square	Significance
8.5509	0.0139 *sig

7. Effect of socio-economic status on money scores

Group	Mean Rank	Cases
I & II	44.16	25
IIIn & IIIm	47.34	35
IV & V	31.52	23

Chi-square	Significance
6.5880	0.0371 *sig

8. Effect of socio-economic status on general knowledge scores

Group	Mean Rank	Cases
I & II	45.52	25
IIIn & IIIm	47.73	35
IV & V	29.46	23

Chi-square	Significance
8.7547	0.0126 *sig

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9. Effect of socio-economic status on leisure activities score

Group	Mean Rank	Cases
I & II	47.80	25
IIIn & IIIm	45.09	35
IV & V	31.00	23

Chi-square	Significance
6.8503	0.0325 *sig

10. Effect of socio-economic status on social contact scores

Group	Mean Rank	Cases
I & II	54.04	25
IIIn & IIIm	36.94	35
IV & V	36.61	23

Chi-square	Significance
8.9938	0.0111 *sig

11. Effect of socio-economic status on social independence score

Group	Mean Rank	Cases
I & II	48.02	25
IIIn & IIIm	40.21	35
IV & V	38.17	23

Chi-square	Significance
2.5115	0.2849 ns

12. Effect of socio-economic status on difficult behaviour score

Group	Mean Rank	Cases
I & II	47.54	25
IIIn & IIIm	41.11	35
IV & V	37.33	23

Chi-square	Significance
2.2475	0.3251 ns

13. Effect of family position in relation to socio-economic status

Analysis of variance

Chi-square	Significance
15.2397	0.4343 ns

14. Effect of socio-economic status in relation to schools

Family Attitude Towards the Child

Results of Mann-Whitney U-Wilcoxon Rank Sum W Tests for each set of scores

1. Sex differences

Group	Mean Rank	Cases
Boys	43.67	46
Girls	36.21	34

U	W	Z	P
636.0	1231.0	-1.4948	0.1350 ns

2. Age Effects

Group	Mean Rank	Cases
Under 14	37.64	42
Over 14	43.66	38

U	W	Z	P
678.0	1659.0	-1.2162	0.2239 ns

3. Influence of family position

Results of Kruskal-Wallis 1-way ANOVA

Group	Mean Rank	Cases
Only child	24.56	8
Eldest	35.68	19
Middle	53.30	10
Youngest	38.94	39

Chi-square	Significance
8.8944	0.0307 *sig

4. Influence of social class

Group	Mean Rank	Cases
I & II	37.38	25
IIIn & IIIm	36.90	34
IV & V	45.19	21

Chi-square	Significance
1.3291	0.5145 *sig

Effect on the Family

Results of Mann-Whitney U-Wilcoxon Rank Sum W Tests for each set of scores

1. Sex differences

Group	Mean Rank	Cases
Boys	38.95	46
Girls	42.60	34

U	W	z	p
710.5	1448.5	-0.7402	0.4592 ns

2. Age Effects

Group	Mean Rank	Cases
Under 14	38.20	42
Over 14	43.04	38

U	W	z	p
701.5	1635.5	-0.9889	0.3227 ns

3. Influence of family position

Results of Kruskal-Wallis 1-way ANOVA

Group	Mean Rank	Cases
Only child	29.63	8
Eldest	37.26	19
Middle	45.65	10
Youngest	39.09	39

Chi-square	Significance
2.7464	0.4324 ns

4. Influence of social class

Group	Mean Rank	Cases
I & II	34.04	25
IIIn & IIIm	44.28	34
IV & V	42.07	21

Chi-square	Significance
2.9274	0.2314 ns

Effect on Brothers and Sisters

Results of Mann-Whitney U-Wilcoxon Rank Sum W Tests for each set of scores

1. Sex differences

Group	Mean Rank	Cases
Boys	36.15	40
Girls	35.81	31

U	W	z	p
614.0	1110.0	-0.0732	0.9417 ns

2. Age Effects

Group	Mean Rank	Cases
Under 14	35.81	35
Over 14	36.18	36

U	W	z	p
623.5	1253.5	-0.0786	0.9373 ns

3. Influence of family position

Results of Kruskal-Wallis 1-way ANOVA

Group	Mean Rank	Cases
Eldest	35.83	18
Middle	40.83	9
Youngest	30.97	38

Chi-square	Significance
3.0229	0.3881 ns

4. Influence of Social Class

Group	Mean Rank	Cases
I & II	37.39	19
IIIn & IIIm	36.13	31
IV & V	34.55	21

Chi-square	Significance
0.1920	0.9085 ns

Spearman Correlation Coefficients for the Full Sample, N=90

Mothers Age	-0.03 (ns)	-0.07 (ns)	-0.05 (ns)	0.05 (ns)	0.14 (ns)	0.02 (ns)	-0.00 (ns)
Family Attitude	-0.25 (p=0.01)	-0.28 (p=0.006)	-0.35 (p=0.001)	-0.28 (p=0.005)	0.03 (ns)	-0.23 (p=0.01)	-0.32 (p=0.001)
Effect on Family	-0.21 (p=0.03)	-0.17 (p=0.06)	-0.26 (p=0.009)	-0.15 (-0.08)	-0.07 (ns)	-0.17 (p=0.05)	-0.25 (p=0.01)
Effect on siblings	-0.16 (ns)	-0.13 (ns)	-0.26 (p=0.01)	-0.04 (ns)	-0.12 (ns)	-0.01 (ns)	-0.08 (ns)
	Communication	Leisure Activities	Social Contact	Social Independence	Difficult Behaviour	ELS	SAS

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Publications available from the Portsmouth Down's Syndrome Trust

Books

1. Buckley, S, Emslie, M, Haslegrave, G, LePrevost, P (1986) The Development of Language and Reading Skills in Children with Down's syndrome.

2. Buckley, S and Sacks, B (1987) The Adolescent with Down's syndrome - Life for the teenager and for the family.

Colour Videotapes

3. Reading skills in children with Down's syndrome (1983). 35 minute tape showing methods of introducing early reading.

4. The Development of Language and Reading Skills in Children with Down's syndrome (1986). A 60 minute tape illustrating the issues discussed in the book above (1).

Order forms and prices available from the Trust Office - address on back cover.

The Portsmouth Down's Syndrome Trust exists to provide support and advice to families from the earliest days and to promote research into the developmental and educational needs of children born with the condition.

The proceeds of all publications support the continued work of the trust.

Back cover photograph
Roberta and her family

ABOUT THE BOOK:- This book is based on the result of a recent survey of ninety teenagers and their families in Hampshire.

The survey was designed to try and find out what life was really like for a teenager with Down's Syndrome and for the family.

The author's discuss the implications of their findings for those who provide education, health care and social services. In doing so they are able to draw on their own wide experience of issues.

Sue Buckley is a Senior Lecturer in Psychology and Director of the Portsmouth Down's Syndrome Trust in the Department of Psychology at Portsmouth Polytechnic. She has many years of experience of mental handicap both as a psychologist and as a parent, as one of her three teenage children is an adopted daughter with Down's Syndrome.

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